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## **Access without Limits - Revisiting Barriers and Boundaries after the Affordable Care Act**

Michael J. DeBoer

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## Article

### Access Without Limits? Revisiting Barriers and Boundaries After the Affordable Care Act

MICHAEL J. DEBOER

*In the United States, the understanding of health care and relationships in the health care and health insurance settings has evolved over the last century. In the past, care for one's own health and the relationships between physicians and patients, hospitals and patients, and health insurers and insureds were understood as matters of private concern. Consequently, individuals were responsible for their own care, and parties voluntarily entered into such relationships relying upon private law, especially contract and tort law, to structure the relationships and define rights and duties. Treating health care as a matter of private concern and these relationships as a matter of private ordering did not, however, ensure sufficiently broad access to health care throughout American society.*

*With the passage of time, public law has become an increasingly employed means of expanding access to care, reducing economic and noneconomic barriers, and securing an environment in which individuals can pursue their own goods (including their own lives and health). Consequently, health care and provider-patient and health insurer-insured relationships have been redefined as matters of both private and public concern, and both private and public law now govern the complex, hybrid blend of private and public ordering that exists in the health care and health insurance settings. Like other public law initiatives enacted in the last century, the Affordable Care Act (ACA) put forward an array of initiatives to increase access to health care, reduce economic and noneconomic barriers, and secure an environment in which individuals can pursue their own goods. In putting forward these initiatives, Congress was cognizant of this hybrid blend of private and public ordering.*

*If the ACA represents something of a culmination of public law efforts to increase access and reduce barriers to care, the present moment is a good time to revisit some of the fundamental considerations, values, and principles that place legitimate limits on the scope of access to care. These considerations, values, and principles suggest that there are boundary areas that should be observed in both private and public law. This Article puts forward two boundary areas for discussion: (1) the professional provider's judgment about medical necessity, effectiveness, and appropriateness; and (2) the provider's judgment on matters of conscience in the provision of care.*

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# Access Without Limits? Revisiting Barriers and Boundaries After the Affordable Care Act

MICHAEL J. DEBOER<sup>\*</sup>

## I. INTRODUCTION

Human life and health are fundamental goods,<sup>1</sup> and political communities play an important role in protecting and promoting these goods.<sup>2</sup> Consequently, increasing access to necessary health care to

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<sup>1</sup> Commentators and philosophers of various stripes have recognized human life and health as fundamental human goods. *See, e.g.*, NORMAN DANIELS, *JUST HEALTH: MEETING HEALTH NEEDS FAIRLY* 29, 77 (2008) (attaching special moral importance to health and arguing that “meeting [health] needs promotes normal functioning, and normal functioning, in turn, protects people’s fair shares of the normal opportunity range. Meeting health needs allows people to choose among the life plans they can reasonably pursue, given their talents and skills.”); JOHN RAWLS, *A THEORY OF JUSTICE* 54 (Oxford Univ. Press 1999) (1971) (identifying health as a natural primary good, which is essential to all life plans); Ronald Dworkin, *Justice in the Distribution of Health Care*, 38 MCGILL L.J. 883, 885, 888, 897–98 (1993) (observing, in discussing the insulation model of health care distribution, that “health care is, as René Descartes put it, chief among all goods[,] that the most important thing is life and health[,] and [that] everything else is of minor importance beside it[,]” but arguing that, with the integration model of health care distribution, health and medical care are not more important goods but rather are brought into competition with other goods such as education, employment, culture, recreation, travel, and experience); John Finnis, *Liberalism and Natural Law Theory*, 45 MERCER L. REV. 687, 691–92 (1994) (identifying the basic human goods as “(1) *knowledge* (including aesthetic appreciation) of reality; (2) *skillful performance*, in work and play, for its own sake; (3) *bodily life* and the component aspects of its fullness: health, vigour and safety; (4) *friendship* or harmony and association between persons in its various forms and strengths; (5) the sexual association of a man and a woman . . . ; (6) the good of harmony between one’s feelings and one’s judgments (inner integrity), and between one’s judgments and one’s behavior (authenticity) . . . [; and] (7) *harmony with the widest reaches and most ultimate source* of all reality, including meaning and value”) [hereinafter Finnis, *Liberalism and Natural Law Theory*]; John Finnis, *Reason, Revelation, Universality and Particularity Ethics*, 53 AM. J. JURIS. 23, 31–32 (2008) (observing that “human wellbeing” has various aspects and basic reasons for action including knowledge, friendship, transmitting human life as parents, and “the intelligible good of human life and health itself”); Samuel Gregg, *Health, Health Care, and Rights: A New Natural Law Theory Perspective*, 25 NOTRE DAME J.L. ETHICS & PUB. POL’Y 463, 466 (2011) (observing that “promoting and protecting health is a self-evident reason for action that requires no further explanation” and that a “choice for good health is . . . an integral element of human flourishing”); *id.* at 469 (stating that “[h]ealth is . . . , from a[] [new natural law theory] standpoint, a fundamental good—a self-evident reason for action”).

<sup>2</sup> *See* Finnis, *Liberalism and Natural Law Theory*, *supra* note 1, at 693 (stating that “the political community . . . is a community cooperating in the service of a common good that is instrumental, . . .

improve the lives and the health of individuals and the population in general, reducing economic and noneconomic barriers to health care, and securing an environment in which individuals can pursue their own goods (including life and health) are worthy policy goals for civil government to pursue. Pursuing these policy goals was a principal aim of Congress in enacting the Affordable Care Act ("ACA"),<sup>3</sup> the comprehensive health reform legislation enacted in 2010.<sup>4</sup> It is projected that initiatives in the ACA will extend health insurance coverage and access to health care to over thirty million Americans and reduce the number of the uninsured by more than half.<sup>5</sup>

In discussing these three policy goals and the ACA, this Article argues three basic points. First, over the last century, health care has evolved from being a matter of private ordering governed by private law to a hybrid blend of private and public ordering governed by both private and public law. During this period, pursuit of the public policy goals of increasing access to health care, reducing barriers, and creating an environment in which individuals can pursue their own goods have guided many of the most important developments in health care law and policy. Second, the ACA put forward an array of access-increasing, barrier-reducing, and environment-altering initiatives that are predicated upon this hybrid blend of private and public ordering but that also amplify the role of public law in ordering relationships in the health care and health insurance settings. Third, even as American society continues to work to increase access, reduce barriers, and secure an environment in which individuals can pursue their own goods, we should revisit some foundational considerations,

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[which is] 'to secure the whole ensemble of material and other conditions, including forms of collaboration, that tend to favour, facilitate, and foster the realization by each individual in that community of his or her personal development' (which will in each case include, constitutively, the flourishing of the family, friendship and other communities to which that person belongs)" (quoting JOHN FINNIS, *NATURAL LAW AND NATURAL RIGHTS* 147 (1980)); *id.* at 697 (stating that "[t]o be sure, the political community is a cooperation which undertakes the unique tasks of giving coercive protection to all individuals and lawful associations within its domain, and of securing an economic and cultural environment in which all these persons and groups can pursue their own proper good").

<sup>3</sup> See *infra* Part III.

<sup>4</sup> The Affordable Care Act ("ACA") is the final amended version of the comprehensive health care reform law that includes the Patient Protection and Affordable Care Act of 2010 ("PPACA"), Pub. L. 111-148, 124 Stat. 119 (2010), and the Health Care and Education Reconciliation Act of 2010 ("HCERA"), Pub. L. No. 111-152, 124 Stat. 1029 (2010), which amended the PPACA. President Barack Obama signed PPACA into law on March 23, 2010, and HCERA into law on March 30, 2010. The ACA enacted major changes to the law governing health care and health insurance in the United States. This Article will reference the Affordable Care Act or the ACA when speaking of the reform legislation collectively.

<sup>5</sup> See Letter from Douglas W. Elmendorf, Dir., Cong. Budget Office, to Hon. Nancy Pelosi, Speaker, U.S. House of Representatives 9-10 (Mar. 20, 2010), available at <http://www.cbo.gov/ftpdocs/113xx/doc11379/AmendReconProp.pdf>; MATTHEW BUETTGENS & MARK A. HALL, "WHO WILL BE UNINSURED AFTER HEALTH INSURANCE REFORM?" 1 (Mar. 2010), available at <http://www.rwjf.org/files/research/71998.pdf>.

values, and principles that have faded into the background and reconsider some boundary areas that legitimately limit access to care.

This Article puts forward for discussion two boundary areas in provider-patient relationships: (1) professional judgments regarding medical necessity, effectiveness, and appropriateness; and (2) provider judgments on matters of conscience.<sup>6</sup> It argues that the law should observe and help to define these boundary areas in clear terms. However, before addressing these two boundary areas, this Article first discusses the evolution of health care from a matter of private ordering to a hybrid blend of private and public ordering and the advancement of access-expanding public policy goals before the ACA.<sup>7</sup> It then examines provisions of the ACA that undertook to increase access to health care, reduce barriers, and secure an environment in which individuals can pursue their own goods.<sup>8</sup>

## II. HEALTH CARE, PRIVATE ORDERING, AND PIECEMEAL PUBLIC REGULATION

The ACA was enacted in an environment in which the rights and duties of patients, physicians, and other providers, as well as the rights and duties of health plans and subscribers, had already been defined by a complex blend of federal and state law and policy. Historically, the physician-patient relationship, the hospital-patient relationship, and the insurer-insured relationship, and along with them access to health care, have been understood as matters of private ordering properly governed by “private law”—especially state contract and tort law.<sup>9</sup> More than three

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<sup>6</sup> See *infra* Part IV. Although other boundary areas may be identified, this Article focuses solely on these two that involve professional/provider judgments.

<sup>7</sup> See *infra* Part II.

<sup>8</sup> See *infra* Part III.

<sup>9</sup> Contract, property, and tort law are among the bodies of private law that allow private ordering among individuals in which legal rights and obligations are voluntarily assumed. See ERNEST J. WEINRIB, *THE IDEA OF PRIVATE LAW* 1, 5, 8, 19 (1995) (describing private law as “connect[ing] two particular parties through the phenomenon of liability,” arguing for the complete autonomy of private law, and observing that private law attends to justice between parties rather than to some social goal or public policy); Barry E. Adler, *The Law of Last Resort*, 55 VAND. L. REV. 1661, 1661–62 (2002) (“The traditional bodies of [private] law that compose private ordering are the laws of property, contract, and tort. Property law establishes private entitlements that can be specifically enforced against the world. Contract law permits individuals to exchange obligations and thus invest one another with entitlements. Tort law creates its own set of entitlements and imposes liability for unwanted interference with those or other entitlements.”); Lan Cao, *Looking at Communities and Markets*, 74 NOTRE DAME L. REV. 841, 841 n.2 (1999) (“Because the public/private distinction emerged from the notion that there is a separate and distinct private order, private law was deemed law that protected ‘pre-political rights. . . . Private law, then, was that part of the legal system protecting the private ordering; public law consisted of government compulsions restricting private freedom.’ . . . Under that definition, property law, tort law, and contract law may be considered examples of private law, and labor law and constitutional law public law.”) (quoting and citing Daniel A. Farber & Philip P. Frickey, *In the Shadow of the Legislature: The Common Law in the Age of the New Public Law*, 89 MICH. L. REV. 875, 886–87

decades ago, one court highlighted this understanding as to the physician-patient relationship:

In the absence of a statute, a physician has no legal obligation to accept as a patient everyone who seeks his services. . . . A physician's duty arises only upon the creation of a physician-patient relationship; that relationship springs from a consensual transaction, a contract, express or implied, general or special, . . . and a patient is entitled to damages resulting from a breach of a physician's duty.<sup>10</sup>

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(1991)); Morton J. Horwitz, *The History of the Public/Private Distinction*, 130 U. PA. L. REV. 1423, 1424 (1982) (explaining that although "there were earlier anticipations of a distinction between public law and private law, only the nineteenth century produced a fundamental conceptual and architectural division in the way we understand the law. One of the central goals of nineteenth century legal thought was to create a clear separation between constitutional, criminal, and regulatory law—public law—and the law of private transactions—torts, contracts, property, and commercial law."); Michael I. Krauss, *Regulation Masquerading as Judgment: Chaos Masquerading as Tort Law*, 71 MISS. L.J. 631, 634–35 (2001) ("Public law, regulating relationships between citizens and the state, is all the rage. Constitutional litigation makes headlines, as it should. . . . It is curious, though, that in a free society like ours private law issues are not more widely recognized as vital. For private law (roughly, rules regulating the allocation of rights and obligations among citizens) and private ordering (the possibility for people to self-determine their rights through private law) are arguably what distinguishes free societies from totalitarian ones. All countries have public law institutions. But only in free countries does private law dominate the acquisition and exchange of rights. Private law does this by allowing citizens to transfer entitlements (i.e., to assume risks) voluntarily through contract law, and involuntarily for two reasons: when one's choices wrongfully cause harm to another (tort law), and when blood or other family ties impose obligations."); Michael I. Krauss, *Tort Law and Private Ordering*, 35 ST. LOUIS U. L.J. 623, 626 (1991) ("Contract law is . . . all about voluntary obligations, or limits on liberty, which are necessary if liberty is to be satisfactorily consummated. . . . Like contract law, tort law results from voluntary acts. . . . Also like contract law, tort law produces legal obligations. Courts force both tortfeasors and recalcitrant contractual debtors to sacrifice their property or part of their liberty."); Roscoe Pound, *Public Law and Private Law*, 24 CORNELL L.Q. 469, 470 (1939) (observing that, in Roman law, "private law had to do with adjusting the relations . . . and determining the controversies between man and man, while public law had to do with the frame of government, the functions of public officials, and adjustment of relations between individuals and the state"). Timothy Jost has noted the preference for private ordering in American society:

As a general matter in our liberal American society, we leave most matters to private ordering, i.e. to private contracts, firms, and associations operating within the framework of social norms and markets, unless there is a good reason to do otherwise. However, no country in the world leaves health-care organization and finance purely to private ordering, and the United States is no exception.

Timothy Stoltzfus Jost, *Health Law and Administrative Law: A Marriage Most Convenient*, 49 ST. LOUIS U. L.J. 1, 23 (2004).

<sup>10</sup> *Lyons v. Grether*, 239 S.E.2d 103, 105 (Va. 1977) (citations omitted). This same court observed that a physician-patient relationship exists when a patient entrusts his or her care to a

Similarly, the hospital-patient relationship and the insurer-insured relationship are contractual in nature.<sup>11</sup> Consequently, the rights and duties in provider-patient relationships and insurer-insured relationships have been understood to be voluntarily undertaken by parties free to enter or refuse to enter into contracts.<sup>12</sup>

#### A. *Increase of Access and Reduction of Barriers*

Although private ordering afforded access to health care and permitted these relationships to be premised on consent and liberty, private ordering did not ensure universal (or near universal) access to health care. Additionally, various barriers made access to health care challenging for many individuals. As the twentieth century unfolded, public law, by which government regulates relationships between government and citizens, compels conduct, and pursues public policy goals and public goods, came to play an increasingly greater role in expanding access, reducing barriers,

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physician and the physician accepts responsibility for that care. *Id.* The physician-patient relationship, once formed, was understood to be of a fiduciary nature requiring the physician to act with utmost care for the patient. *See, e.g.,* Nardone v. Reynolds, 538 F.2d 1131, 1136 (5th Cir. 1976) (observing that “[w]hen a patient is treated by a series of surgeons and doctors the fiduciary relationship exists regardless of whether the patient is aware who is treating him. This Hippocratic duty is born out of the doctor’s purpose to render professional service.”); Davis v. Rodman, 227 S.W. 612, 614 (Ark. 1921) (stating that “[t]he relation of a physician to his patient and the immediate family is one of the highest trust”).

<sup>11</sup> As to the hospital-patient relationship, one court has explained that the “essence of the contractual relationship between hospital and patient is readily apparent; the patient bargains for, and the hospital agrees to make available, the human skill and physical materiel of medical science to the end that the patient’s health be restored.” *Perlmutter v. Beth David Hosp.*, 123 N.E.2d 792, 794 (N.Y. 1954). As to the insurer-insured relationship, courts have long recognized that “an insurance policy is a contract, and . . . the relationship between the insurer and the insured is purely contractual in nature.” *Nationwide Mut. Ins. Co. v. Marsh*, 472 N.E.2d 1061, 1062 (Ohio 1984) (*per curiam*). Another court has observed that a “group insurance contract is primarily a contract between the employer and the insurer[, but] some courts have held that there is a contractual relationship between the insured employees and the insurer, often created when the employee contributes to premium payment.” *Abbiati v. Buttura & Sons, Inc.*, 639 A.2d 988, 990 (Vt. 1994) (citations omitted).

<sup>12</sup> *See, e.g.,* Hurley v. Eddingfield, 59 N.E. 1058, 1058 (Ind. 1901) (“The act regulating the practice of medicine provides for a board of examiners, standards of qualification, examinations, licenses to those found qualified, and penalties for practicing without license. . . . The act is a preventive, not a compulsive, measure. In obtaining the state’s license (permission) to practice medicine, the state does not require, and the licensee does not engage, that he will practice at all or on other terms than he may choose to accept. Counsel’s analogies, drawn from the obligations to the public on the part of innkeepers, common carriers, and the like, are beside the mark.”) (internal citation omitted); *Ortiz v. Glusman*, 334 S.W.3d 812, 817 (Tex. Ct. App. 2011) (“In medical-malpractice cases, a physician-patient relationship is a prerequisite to the existence of any duty. . . . To establish such a relationship, the physician need not have direct physical contact with the patient. . . . Indeed, a physician-patient relationship may be established at the express or implied consent of the physician. . . . However, merely being ‘on call’ does not automatically create a physician-patient relationship, nor does it impose a duty. . . . When there is no prior relationship between the physician and the patient, there must be some affirmative action on the part of the physician to treat the patient to create such a relationship.”) (internal citations omitted).



and altering the health care environment so that individuals could better pursue their own goods.

### 1. *Economic Barriers*

Economic barriers have hindered access to health care. At the beginning of the twentieth century, patients paid for most health care services and treatment on a fee-for-service basis out of their own pockets,<sup>13</sup> and consequently those who lacked the financial ability to pay for medical care had limited access and received limited care. During the Depression era, as patients struggled to afford health care services and as hospitals and physicians experienced a shortage of patients to treat, health insurance emerged as a means of financing health care.<sup>14</sup> With the passage of time, employers increasingly began to offer health insurance as a fringe benefit, which the federal government had determined to be exempt from wage and price controls in the 1940s.<sup>15</sup> Congress approved this development by extending favorable tax treatment under the Internal Revenue Code to employer-provided health insurance in two ways: (1) by permitting employers to deduct the premiums they pay as ordinary and necessary business expenses; and (2) by excluding employer contributions to employer-provided health plans from the taxable income of employees.<sup>16</sup>

Not all Americans, however, had access to employer-provided health insurance. With elderly and poor Americans, Congress acted to make health insurance more readily available by establishing the Medicare and Medicaid programs in the Social Security Amendments of 1965.<sup>17</sup> In 1972, Congress expanded the Medicare program to cover many disabled Americans and individuals with End Stage Renal Disease.<sup>18</sup> In 1997,

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<sup>13</sup> See Randall R. Bovbjerg et al., *U.S. Health Care Coverage and Costs: Historical Development and Choices for the 1990s*, 21 J.L. MED. & ETHICS 141, 141–42 (1993) (outlining the history of health insurance in the United States).

<sup>14</sup> BARRY R. FURROW ET AL., *HEALTH LAW* § 9-1 (2d ed. 2000).

<sup>15</sup> See David A. Hyman & Mark Hall, *Two Cheers for Employment-Based Health Insurance*, 2 YALE J. HEALTH POL'Y L. & ETHICS 23, 25 (2001); Kathryn L. Moore, *The Future of Employment-Based Health Insurance After the Patient Protection and Affordable Care Act*, 89 NEB. L. REV. 885, 887–90 (2011).

<sup>16</sup> See 26 U.S.C. § 162(a) (2006) (permitting a deduction for ordinary and necessary expenses, including “a reasonable allowance for salaries or other compensation for personal services actually rendered”); *id.* § 105 (excluding from gross income amounts received under accident and health plans); *id.* § 106 (excluding from gross income contributions by employer to accident and health plans).

<sup>17</sup> See Social Security Amendments of 1965, Pub. L. No. 89-97, § 102(a), 79 Stat. 286, 291 (codified as amended at 42 U.S.C. §§ 1395–1395kkk-1) (Medicare); Social Security Amendments of 1965, Pub. L. No. 89-97, § 102(a), 79 Stat. 286, 343 (codified as amended at 42 U.S.C. §§ 1396–1396w-5) (Medicaid). In the Social Security Amendments, the Medicare and Medicaid programs were adopted as Title XVIII and Title XIX, respectively, of the Social Security Act, which Congress had enacted decades earlier to establish various federal social welfare programs, including Social Security retirement and disability insurance programs. Social Security Act, 42 U.S.C. §§ 300–1397.

<sup>18</sup> Social Security Amendments of 1972, 42 U.S.C. § 1395c.

Congress created the Children's Health Insurance Program to encourage states to provide health insurance to uninsured children.<sup>19</sup> Then, in 2003, Congress added an optional prescription-drug benefit to the Medicare program.<sup>20</sup>

As a consequence of these developments with both employer-provided plans and public health insurance programs, health insurance emerged during the twentieth century as the principal means of financing and ensuring access to health care in the United States.<sup>21</sup> The growth of health insurance as the principal means of financing health care contributed to a redefinition of health care as not simply a matter of private good and private ordering, but also a matter of public good and public ordering warranting state and federal regulation by public law.<sup>22</sup>

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<sup>19</sup> Congress created the Children's Health Insurance Program ("CHIP") as Title XXI of the Social Security Act. Balanced Budget Act of 1997, Pub. L. No. 105-33, 111 Stat. 251 (codified as amended in scattered sections of U.S.C. tits. 2, 8, 26, 38, 40 & 42). The Children's Health Insurance Program Reauthorization Act of 2009 ("CHIPRA") reauthorized CHIP and financed the program through fiscal year 2013. Children's Health Insurance Program Reauthorization Act of 2009, Pub. L. No. 111-3, 123 Stat. 8 (codified as amended in scattered sections of 42 U.S.C.).

<sup>20</sup> Medicare Prescription Drug, Improvement, and Modernization Act of 2003, 42 U.S.C. § 1395w-101.

<sup>21</sup> See generally FURROW ET AL., *supra* note 14, § 8-1 (identifying employer provided health insurance as "the dominant vehicle for private finance of health care in the United States"); *id.* § 9-1 (discussing the development of private health insurance during the twentieth century in the United States and noting that, in 1997, some form of private insurance covered 188.5 million Americans); *id.* § 11-1 (discussing the establishment and rise of the federal Medicare program as the largest single government health insurance program); *id.* § 12-1 (discussing Medicaid as a cooperative federal state program for financing health care for the poor); Eleanor D. Kinney, *Recognition of the International Human Right to Health and Health Care in the United States*, 60 RUTGERS L. REV. 335, 356 (2008) (stating that "[h]ealth insurance coverage is the most important means for assuring that individuals have access to expensive health care services").

<sup>22</sup> Although Congress embraced employer-provided health benefits as a health care financing mechanism in its favorable treatment of employer-provided health benefits in the Internal Revenue Code and in its enactment of the Employee Retirement Income Security Act of 1975 ("ERISA"), states have traditionally been recognized to possess authority to regulate insurance pursuant to their general police power to protect the health, morals, safety, and general welfare of citizens. See *Magellan Health Servs., Inc. v. Highmark Life Ins. Co.*, 755 N.W.2d 506, 513 (Iowa 2008) (discussing provisions of the Iowa Code and the Iowa Administrative Code and stating that "promoting the availability of health insurance coverage to persons who might not otherwise obtain it is within the scope of police powers traditionally left to state regulation") (citing *De Buono v. NYSA-ILA Med. & Clinical Servs. Fund*, 520 U.S. 806, 814 (1997)); *Swearingen v. Bond*, 122 S.E. 539, 540 (W. Va. 1924) (stating that "[t]he insurance business is quasi public in its character, and the state may, under its police power, determine who may engage in the business, and prescribe the terms and conditions on which it may be conducted, and generally to regulate it and all persons engaged in it"); Elizabeth Weeks Leonard, *Rhetorical Federalism: The Value of State-Based Dissent to Federal Health Reform*, 39 HOFSTRA L. REV. 111, 152 (2011) (observing that "[i]nsurance regulation was long considered within core state police powers to protect the health, safety, and welfare of their citizens" and noting the Congressional affirmation of that understanding in the McCarran-Ferguson Act); see also *Gonzales v. Oregon*, 546 U.S. 243, 270 (2006) ("[T]he structure and limitations of federalism . . . allow the States 'great latitude under their police powers to legislate as to the protection of the lives, limbs, health, comfort, and quiet of all persons.'") (quoting *Medtronic, Inc. v. Lohr*, 518 U.S. 470, 475 (1996)); *Clem v. Christole, Inc.*, 582

Because of concerns regarding the coverage of benefits and the portability of health insurance, state and federal legislatures acted to adjust rights and duties under health insurance plans. For instance, many states enacted statutes to mandate that health insurance plans cover or offer coverage of certain benefits, patient populations, and providers.<sup>23</sup> Additionally, Congress enacted the Consolidated Omnibus Budget Reconciliation Act of 1985 (“COBRA”) providing for the continuation of employer-provided health insurance after employment termination. Under COBRA, employees of certain private and state or local government employers, as well as their dependents, who would otherwise lose their health insurance coverage, may continue their coverage for specified periods of time.<sup>24</sup> In the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”), Congress improved the portability and the continuity of coverage for those who obtain insurance through employer-provided plans or the individual market.<sup>25</sup> Among other things, HIPAA limits the ability of health plans to restrict coverage of preexisting conditions,<sup>26</sup> and it prohibits discrimination by health plans based upon the health status-related characteristics of insured individuals and their dependents.<sup>27</sup>

In addition to laws intended to reduce economic barriers to care by making health insurance more readily available, other state and federal laws and regulations addressed economic barriers by other means. For instance, out of a concern that the supply of medical facilities and services was inadequate in certain areas of the country, in 1946 Congress enacted the Hill-Burton Act to promote the modernization of health care by

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N.E.2d 780, 782–83 (Ind. 1991) (recognizing the police power of the state as “the power inherent in a government to enact laws, within constitutional limits, to promote the order, safety, health, morals, and general welfare of society”) (quoting *Bruck v. State ex rel. Money*, 91 N.E.2d 349, 352 (Ind. 1950)).

<sup>23</sup> State health insurance mandates include requirements that health plans cover certain benefits (such as mammograms, pediatric care, and drug and alcohol abuse treatment), certain patient populations (such as adopted children, non-custodial children, and students up to a certain age on their parents’ insurance), and certain providers (such as chiropractors, podiatrists, and massage therapists); see also FURROW ET AL., *supra* note 14, 9–4b; VICTORIA CRAIG BUNCE & J.P. WIESKE, COUNCIL FOR AFFORDABLE HEALTH INSURANCE, HEALTH INSURANCE MANDATES IN THE STATES 2010 (2010). In 2010, the number of state health insurance mandates rose to 2156, up from 2133 in 2009. Victoria Craig Bunce & J.P. Wieske, Executive Summary, Health Insurance Mandates in the States 2010 1 (2010), available at [http://www.cahi.org/cahi\\_contents/resources/pdf/MandatesintheStates2010ExecSummary.pdf](http://www.cahi.org/cahi_contents/resources/pdf/MandatesintheStates2010ExecSummary.pdf). Among the states, Rhode Island, Maryland, Minnesota, Texas, and Connecticut have imposed the greatest number of mandates, while Idaho, Alabama, Hawaii, Michigan, and Utah have the fewest mandates. *Id.* at 3.

<sup>24</sup> 29 U.S.C. §§ 1161–68 (2006); 42 U.S.C. §§ 300bb-1 to 300bb-8 (2006).

<sup>25</sup> 29 U.S.C. §§ 1181–82; 42 U.S.C. § 300gg-41.

<sup>26</sup> 29 U.S.C. § 1181(a); 42 U.S.C. § 300gg-3.

<sup>27</sup> 29 U.S.C. § 1182(a) & (b).

providing funding for the construction of medical facilities.<sup>28</sup> Congress intended the funding authorized by this act to assist states in carrying out their programs for the construction and modernization of hospitals and to stimulate the development of new or improved medical facilities.<sup>29</sup> However, Congress also intended that hospitals receiving funding would make their facilities available to all persons residing in their areas and provide services to persons who are unable to pay for the services.<sup>30</sup>

In 1956, the Internal Revenue Service issued a revenue ruling specifying the criteria that apply in determining whether a hospital qualifies for exemption from income taxation as a public charitable organization under § 501(c)(3) of the Internal Revenue Code.<sup>31</sup> In addition to other requirements, the ruling required that the hospital be “organized as a nonprofit charitable organization for the purpose of operating a hospital for the care of the sick,”<sup>32</sup> and that the hospital, “to the extent of its financial ability,” “be operated” for those who are not able to pay for their services and “not exclusively” for those who can pay and are expected to pay.<sup>33</sup> In 1969, just a few years after the creation of the Medicare and Medicaid programs, the IRS issued a new revenue ruling that adjusted the criteria for determining federal income tax exemption for hospitals and shifted the focus from relief for the poor to the promotion of the health of the community.<sup>34</sup> Among the factors considered under the community benefit standard are whether a hospital operates a full-time emergency room open to all persons regardless of ability to pay and whether the hospital provides care for those in their community who are able to pay either directly or through third-party reimbursement (including Medicare and Medicaid patients).<sup>35</sup> Additionally, a number of states have enacted

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<sup>28</sup> See Hospital Survey and Construction Act, Pub. L. No. 79-725, Titles VI & XVI, 60 Stat. 1040 (1946) (codified as amended in scattered sections of 42 U.S.C.).

<sup>29</sup> 42 U.S.C. § 291.

<sup>30</sup> *Id.* § 291c(e)(2).

<sup>31</sup> Rev. Rul. 56-185, 1956-1 C.B. 202; *see also* 26 U.S.C. § 501(c)(3) (2006).

<sup>32</sup> Rev. Rul. 56-185, *supra* note 31, at 1.

<sup>33</sup> *Id.* at 2.

<sup>34</sup> Rev. Rul. 69-545, 1969-2 C.B. 117. In establishing the community benefit standard, the IRS recognized the promotion of health as a charitable purpose like other recognized exempt purposes

that is deemed beneficial to the community as a whole even though the class of beneficiaries eligible to receive a direct benefit from its activities does not include all members of the community, such as indigent members of the community, provided that the class is not so small that its relief is not of benefit to the community.

*Id.* at 3 (citing RESTATEMENT (SECOND) OF TRUSTS §§ 368 cmt. b & 372 cmts. b & c; 4 SCOTT ON TRUSTS §§ 368 & 372.2 (3d ed. 1967)).

<sup>35</sup> The community benefit standard also includes the following factors: maintaining a sufficiently open medical staff depending on the size and nature of the facility; using surplus funds to improve

legislation requiring tax-exempt hospitals to provide their communities greater public benefits by mandating that they conduct and report the results of community health needs assessments and develop community health benefit plans, or by mandating that they provide a minimum amount of charity care.<sup>36</sup>

In 1986, Congress enacted the Emergency Medical Treatment and Active Labor Act (“EMTALA”) to address a concern that some hospitals were “dumping” certain patients who were in need of care after the hospitals learned that the patients lacked health insurance or were otherwise unable to pay for their care.<sup>37</sup> EMTALA requires hospitals with emergency departments that participate in the Medicare program to provide medical screening and stabilizing care to patients with emergency medical conditions or in active labor who come to their emergency departments, without regard to any patient’s insurance status or ability to pay.<sup>38</sup> Through the common law or by statute, many states have also recognized that hospitals bear a duty to provide emergency care.<sup>39</sup>

## 2. Noneconomic Barriers

In addition to economic barriers, noneconomic barriers to health care have also hindered access to health care, and a patchwork of federal and state laws has been enacted to reduce some of these noneconomic barriers. For instance, Congress enacted Title VI of the Civil Rights Act of 1964 prohibiting discrimination on the basis of race, color, and national origin in

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patient care, facilities, equipment, and medical training, education, and research programs; and being governed by a board comprised of independent community leaders. Rev. Rul. 69-545, *supra* note 34, at 3.

<sup>36</sup> See John D. Colombo, *Federal and State Tax Exemption Policy, Medical Debt and Healthcare for the Poor*, 51 ST. LOUIS U. L.J. 433, 440–46 (2007) (identifying states that have adopted community benefit reporting statutes); see also Evelyn Brody, *All Charities are Property-Tax Exempt, but Some Charities are More Exempt than Others*, 44 NEW ENG. L. REV. 621, 671–732 (2010) (providing a state-by-state survey). Indiana, for instance, requires a nonprofit hospital to develop an organizational mission statement that identifies the hospital’s commitment to serve community health care needs and an operational plan for serving community health care needs, to consider community health care needs as determined by a community-wide needs assessment, to annually file a report regarding its plan with the state health department, and to develop a written notice about any charity care program operated by the hospital and how to apply for charity care that is conspicuously posted. IND. CODE §§ 16-21-9-4, -5, & -7 (2008). Texas, by statute, established specific requirements that nonprofit hospitals must meet to qualify as charitable organizations, including a standard that charity care and government-sponsored indigent health care be provided in an amount equal to at least four percent of their net patient revenue. TEX. TAX. CODE ANN. § 11.1801(a) (West 2008).

<sup>37</sup> See Comprehensive Omnibus Budget Reconciliation Act of 1985 (“COBRA”), 42 U.S.C. § 1395dd (2006). EMTALA was enacted as a part of COBRA.

<sup>38</sup> 42 U.S.C. § 1395dd.

<sup>39</sup> See Andrew Jay McClurg, *Your Money or Your Life: Interpreting the Federal Act Against Patient Dumping*, 24 WAKE FOREST L. REV. 173, 183 & n.51, 188–97 (1989) (discussing duty to provide emergency care under state law); see generally Karen H. Rothenberg, *Who Cares?: The Evolution of the Legal Duty to Provide Emergency Care*, 26 HOUS. L. REV. 21 (1989).

any program or facility that receives federal funding.<sup>40</sup> Title VI applies to hospitals, clinics, nursing homes, and other health care institutions receiving federal funding, such as under the Hill-Burton Act or through the Medicare/Medicaid programs.<sup>41</sup> Section 504 of the Rehabilitation Act and the Americans with Disabilities Act prohibit discrimination based on disability.<sup>42</sup> Congress intended these two acts to reduce the disabilities barrier to health care in programs and services that receive federal funding, as well as in private programs and services, including hospitals and physician practices.<sup>43</sup> In their antidiscrimination statutes, some states have prohibited discrimination on the basis of disability, national origin, race, religion, and sex by any places of public accommodations, which would include most health care providers.<sup>44</sup>

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<sup>40</sup> Civil Rights Act of 1964, 42 U.S.C. §§ 2000d to 2000d-4a. *Id.* § 2000d (“No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”).

<sup>41</sup> See FURROW ET AL., *supra* note 14, §§ 10-18, 10-19; Sidney D. Watson, *Reinvigorating Title VI: Defending Health Care Discrimination—It Shouldn’t Be so Easy*, 58 FORDHAM L. REV. 939, 943–48 (1990); Ruqaiijah Yearby, *Litigation, Integration, and Transformation: Using Medicaid to Address Racial Inequities in Health Care*, 13 J. HEALTH CARE L. & POL’Y 325, 328–29 (2010); Ruqaiijah Yearby, *Striving for Equality, but Settling for the Status Quo in Health Care: Is Title VI More Illusory than Real?*, 59 RUTGERS L. REV. 429, 443–44 (2007).

<sup>42</sup> Rehabilitation Act of 1973, 29 U.S.C. § 794 (2006); Americans with Disabilities Act of 1990 (ADA), 42 U.S.C. §§ 12181–89. Section 504 of the Rehabilitation Act provides in relevant part that “[n]o otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency . . . .” 29 U.S.C. § 794(a). Title III of the ADA provides in relevant part that “[n]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation.” 42 U.S.C. § 12182(a).

<sup>43</sup> See FURROW ET AL., *supra* note 14, §§ 10-20 to 10-22.

<sup>44</sup> For instance, Wisconsin law prohibits any person to “[d]eny to another or charge another a higher price than the regular rate for the full and equal enjoyment of any public place of accommodation or amusement because of sex, race, color, creed, disability, sexual orientation, national origin or ancestry” or to “[g]ive preferential treatment to some classes of persons in providing services or facilities in any public place of accommodation or amusement because of sex, race, color, creed, sexual orientation, national origin or ancestry.” WIS. STAT. §§ 106.52(3)(a)1, (3)(a)2 (2012). Wisconsin law defines “public place of accommodation or amusement” “broadly to include” a wide range of places of business, places of recreation, and establishments as well as nursing homes, clinics, hospitals, and “any place where accommodations, amusement, goods or services are available either free or for a consideration . . . .” *Id.* § 106.52(1)(e)1; see also N.J. STAT. ANN. § 10:1-2 (West 2002) (recognizing the entitlement of all persons within the jurisdiction of the state “to the full and equal accommodations, advantages, facilities and privileges of any places of public accommodation, resort or amusement”); *id.* § 10:1-3 (prohibiting exclusion from any of the accommodations, advantages, facilities, or privileges “on account of race, creed, color, national origin, ancestry, marital status or sex,” with some exceptions); *id.* § 10:1-5 (broadly defining a place of public accommodation, resort, or amusement to include *inter alia* any “dispensary, clinic, [or] hospital”).

### B. *Alteration of the Health Care Environment*

Public law has also played a role in securing an environment in which individuals can pursue their own goods (including life and health). A number of the legal developments mentioned above, such as the laws promoting the widespread availability of health insurance, the laws increasing the supply and availability of medical facilities, and the laws prohibiting discrimination based upon race, national origin, and disability, have had an environment-altering impact ensuring that more individuals can pursue their own goods. Additionally, under state and federal law and regulation, standards have been developed to govern provider-maintenance of patient records, permit patients access to their records, require providers to maintain the confidentiality of patient information, and safeguard patient health information.<sup>45</sup>

Furthermore, during the twentieth century, courts applying contract and tort law concepts developed a doctrine of informed consent. This doctrine—which is predicated upon principles of patient autonomy, human dignity, personal inviolability, bodily integrity, and consent—requires health care providers to disclose information to their patients and to obtain their patients' informed consent before they perform procedures or provide treatment.<sup>46</sup> Many state legislatures have built upon this judicial, private-

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<sup>45</sup> See generally FURROW ET AL., *supra* note 14, §§ 4-29 to 4-38 (discussing state and federal standards regulating confidentiality and disclosure of medical information and records); Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451, 499-513 (1995) (reviewing legislative and regulatory protection of informational privacy and common-law protection of health informational privacy). In the Health Insurance Portability and Accountability Act of 1996, Congress sought, in addition to improving continuity and portability of health insurance coverage, to encourage the expanded use of electronic record-keeping methods in health care and develop standards for the electronic transmission of health information, while at the same time safeguarding the privacy of health records. Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), Pub. L. No. 104-191, 110 Stat. 1936 (codified as amended in scattered sections of 18, 26, 29, and 42 U.S.C.). After Congress failed to finalize a comprehensive privacy rule, the Secretary of Health and Human Services developed and promulgated a privacy rule that governs the use and disclosure of individually identifiable health information. Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82,462 (Dec. 28, 2000) (codified at 45 C.F.R. pts. 160, 164).

<sup>46</sup> See, e.g., *Canterbury v. Spence*, 464 F.2d 772, 782-83 (D.C. Cir. 1972) (stating that "the physician must seek and secure his patient's consent before commencing an operation or other course of treatment[.]" that "the consent, to be efficacious, must be free from imposition upon the patient[.]" that "therapy not authorized by the patient may amount to a tort—a common law battery—by the physician[.]" that "it is normally impossible to obtain a consent worthy of the name unless the physician first elucidates the options and the perils for the patient's edification[.]" and that "the physician has long borne a duty, on pain of liability for unauthorized treatment, to make adequate disclosure to the patient"); *Cobbs v. Grant*, 502 P.2d 1, 9-10 (Cal. 1972) (recognizing that "patients are generally persons unlearned in the medical sciences," that generally "the knowledge of patient and physician are not in parity[.]" that "a person of adult years and in sound mind has the right, in the exercise of control over his own body, to determine whether or not to submit to lawful medical treatment[.]" that "the patient's consent to treatment, to be effective, must be an informed consent[.]" and that "the patient, being unlearned in medical sciences, has an abject dependence upon and trust in

law foundation by enacting legislation that recognizes the authority of adult individuals to consent to their own health care<sup>47</sup> and legislation that sets forth specific requirements for providers to obtain informed consent from their patients.<sup>48</sup> Under state law, health care providers must disclose various factors: the diagnosis or general nature of the patient's condition; the nature and purpose of the proposed procedure or treatment; the material risks; the expected outcomes; the likelihood of success; the practical or reasonable alternatives; and the prognosis if the procedure or treatment is declined.<sup>49</sup> In 1990, Congress enacted the Patient Self-Determination Act requiring certain health care providers that receive Medicare and Medicaid funding to maintain written policies and procedures to provide information to patients regarding their rights under state law to make decisions regarding their medical care, to document in patient records whether a patient has executed an advance directive, and to ensure compliance with state law requirements regarding advance directives.<sup>50</sup>

As described above, during the twentieth century, pursuit of the

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his physician for the information upon which he relies during the decision process, thus raising an obligation in the physician that transcends arms-length transactions[.]" and holding that "as an integral part of the physician's overall obligation to the patient there is a duty of reasonable disclosure of the available choices with respect to proposed therapy and of the dangers inherently and potentially involved in each"); *Mohr v. Williams*, 104 N.W. 12, 14-15 (Minn. 1905) ("It cannot be doubted that ordinarily the patient must be consulted, and his consent given, before a physician may operate upon him. . . . Under a free government, at least, the free citizen's first and greatest right, which underlies all others—the right to the inviolability of his person; in other words, the right to himself—is the subject of universal acquiescence, and this right necessarily forbids a physician or surgeon, however skillful or eminent, who has been asked to examine, diagnose, advise, and prescribe (which are at least necessary first steps in treatment and care), to violate, without permission, the bodily integrity of his patient by a major or capital operation, placing him under an anaesthetic for that purpose, and operating upon him without his consent or knowledge. . . . Consent . . . of an individual[] must be either expressly or impliedly given before a surgeon may have the right to operate. . . . [C]ontracts are entered into by the mutual agreement of the interested parties, and are required to be performed in accordance with their letter and spirit. . . . If the physician advises his patient to submit to a particular operation, and the patient weighs the dangers and risks incident to its performance, and finally consents, he thereby, in effect, enters into a contract authorizing his physician to operate to the extent of the consent given, but no further.") (internal quotation marks and citations omitted), *overruled on other grounds* *Genzel v. Halvorson*, 80 N.W.2d 854 (1957); *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914) (observing that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages"), *abrogated on other grounds* *Bing v. Thunig*, 143 N.E.2d 3 (N.Y. 1957).

<sup>47</sup> See, e.g., IND. CODE § 16-36-1-3 (2008).

<sup>48</sup> See, e.g., GA. CODE ANN. § 31-9-6.1 (2010) (requiring disclosure of information and consent to certain surgical and diagnostic procedures); IND. CODE § 34-18-12-2 (providing that a rebuttable presumption that consent is informed arises when a patient's written consent is signed by the patient or the patient's representative, witnessed by an individual eighteen years of age or older, and explained orally or in the written consent before a treatment, procedure, examination, or test is undertaken).

<sup>49</sup> See, e.g., GA. CODE § 31-9-6.1(a); IND. CODE § 34-18-12-3 (2008).

<sup>50</sup> Omnibus Budget Reconciliation Act of 1990, 42 U.S.C. §§ 1395cc(f) & 1396a(w) (2006). The Patient Self-Determination Act was passed as part of the Omnibus Budget Reconciliation Act of 1990.



access-increasing, barrier-reducing, and environment-altering public policy goals led to the enactment and development of public laws and regulations that have had a public-ordering impact on physician-patient relationships, hospital-patient relationships, and insurer-insured relationships. Indeed, during the twentieth century, public law came to play an increasingly greater role in defining rights and duties in these relationships. Nevertheless, although public law adjusted and, in significant ways, re-ordered and redefined the duties of physicians, other providers, and health plans, as well as the rights of patients and subscribers, public law did not displace the traditional notion that these relationships are, in significant (if not major) part, a matter of private ordering governed by private law. Furthermore, although our understanding of relationships in the health care and health insurance settings has evolved from a more traditional private ordering/private law conception to a hybrid conception involving private and public ordering and private and public law, efforts to increase access, reduce barriers, and alter the health care environment have not hardened into a general, recognized legal right to health care. Indeed, no general legal right to health care exists under federal law or the law of most states,<sup>51</sup> and thus, generally speaking, there is no legal right to health

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<sup>51</sup> The United States Supreme Court has not recognized a positive right to health care under the United States Constitution, and consequently the Constitution generally does not require states to provide or pay for the health care of its citizens. See *Maier v. Roe*, 432 U.S. 464, 469–70 (1977) (stating that “[t]he Constitution imposes no obligation on the States to pay the pregnancy-related medical expenses of indigent women, or indeed to pay any of the medical expenses of indigents. But when a State decides to alleviate some of the hardships of poverty by providing medical care, the manner in which it dispenses benefits is subject to constitutional limitations.”); see also *Wideman v. Shallowford Cmty. Hosp., Inc.*, 826 F.2d 1030, 1032–33 (11th Cir. 1987) (“Beginning from the broadest perspective, we can discern no general right, based upon either the Constitution or federal statutes, to the provision of medical treatment and services by a state or municipality. If such a right exists at all, it must derive from the fourteenth amendment’s due process clause, which forbids a state to deprive anyone of life, liberty or property without due process of law. The due process clause, however, has traditionally been interpreted as protecting certain ‘negative liberties,’ *i.e.*, an individual’s right to be free from arbitrary or discriminatory action taken by a state or municipality. This circuit has recognized the ‘well established notion that the Constitution limits the actions the states can take rather than mandating specific obligations.’”) (quoting *Bradberry v. Pinellas County*, 789 F.2d 1513, 1517 (11th Cir. 1986)). Citing *Maier*, and *Roe v. Wade*, 410 U.S. 113 (1973), the Eleventh Circuit observed that “two Supreme Court decisions dealing with access to abortions also support our conclusion that there is no general right to medical care or treatment provided by the state.” *Wideman*, 826 F.2d at 1033; see also *DeShaney v. Winnebago Cnty. Dep’t of Soc. Servs.*, 489 U.S. 189, 196 (1989) (stating that “the Due Process Clauses generally confer no affirmative right to governmental aid, even where such aid may be necessary to secure life, liberty, or property interests of which the government itself may not deprive the individual”). Nevertheless, the Constitution does require states to provide adequate medical care to incarcerated prisoners, *Estelle v. Gamble*, 429 U.S. 97, 103–04 (1976), and involuntarily committed mental patients, *Youngberg v. Romeo*, 457 U.S. 307, 314–25 (1982), who are in state custody against their will and unable to care for themselves. Additionally, the state of Vermont has recently passed legislation recognizing the right to health care. See VT. STAT. ANN. tit. 3, § 2222a(c)(8) (2010) (stating that Vermont’s health care system reform efforts include creating “a universal health system to provide affordable, high-quality health care coverage to all Vermonters”);

care.<sup>52</sup>

### III. THE ACA, INCREASED ACCESS, REDUCED BARRIERS, AND AN “INDIVIDUAL GOOD”-PROMOTING ENVIRONMENT

In the ACA, Congress pursued these same three public policy goals of increasing access to health care, reducing barriers, and securing an environment in which individuals can seek their own goods.<sup>53</sup> Indeed,

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VT. STAT. ANN. tit. 18, § 9371(1) (2002) (articulating various principles to guide the state’s health care reform efforts including that the state “must ensure universal access to and coverage for high-quality, medically necessary health services for all Vermonters[,]” that “[s]ystemic barriers, such as cost, must not prevent people from accessing necessary health care[,]” and that “[a]ll Vermonters must receive affordable and appropriate health care at the appropriate time in the appropriate setting”); *id.* § 9401(a) (declaring that “[i]t is the policy of the state of Vermont that health care is a public good for all Vermonters and to ensure that all residents have access to quality health services at costs that are affordable”); Mariah McGill, *The Human Right to Health Care in the State of Vermont*, 37 VT. B.J. 28 (2011). Furthermore, although a right to health has been recognized in international law, that international right has not been formally ratified or recognized in the United States. See Kinney, *supra* note 21 (discussing the Constitution of the World Health Organization, the United Nations Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, and other documents).

<sup>52</sup> In addition to arguments for a right to health care premised upon constitutional sources, some scholars have argued forcefully for a moral right to health care. See, e.g., TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 239–50 (5th ed. 2001); DANIELS, *supra* note 1, at 313–32.

<sup>53</sup> It is the means that Congress chose, and not the ends that Congress sought, that have posed the greatest challenges for the legislation. For instance, the individual mandate, which requires most individuals to purchase health insurance, has spawned litigation challenging the constitutionality of the ACA and the scope of Congress’s enumerated power under the Commerce Clause. See *Florida ex rel. Bondi v. U.S. Dep’t of Health & Human Servs.*, 780 F. Supp. 2d 1256 (N.D. Fla. 2011), *aff’d in part, rev’d in part* *Florida ex rel. Att’y Gen. v. U.S. Dep’t of Health & Human Servs.*, 648 F.3d 1235 (11th Cir. 2011), *cert granted in part* 132 S. Ct. 604 (2011), and *Florida ex rel. McCollum v. U.S. Dep’t of Health & Human Servs.*, 716 F. Supp. 2d 1120 (N.D. Fla. 2010), *aff’d in part, rev’d in part* *Florida ex rel. Att’y Gen.*, 648 F.3d 1235, *cert granted in part* 132 S. Ct. 604; see also *Virginia ex rel. Cuccinelli v. Sebelius*, 728 F. Supp. 2d 768 (E.D. Va. 2010), *rev’d* *Virginia ex rel. Cuccinelli v. Sebelius*, 656 F.3d 253 (4th Cir. 2011), and *Virginia ex rel. Cuccinelli v. Sebelius*, 702 F. Supp. 2d 598 (E.D. Va. 2010), *rev’d* 656 F.3d 253. Implementation of these means poses challenges. See JOHN E. McDONOUGH, *INSIDE NATIONAL HEALTH REFORM* 103 (2011) (observing that each title of a federal law has “its own purpose, shape, identity, history, assumptions—data-based and otherwise—and curiosities. Some fit comfortably into the whole act or statute, and some stick out at an odd angle. Some may look pretty darn appealing during markup or floor consideration and then take on a ghastly appearance once implementation time rolls around. One senior House staffer likened the [ACA] to a garden packed with a wide array of plants. Some will grow grand and plentiful as intended, some will never grow at all—unexpectedly or as intended—while others will grow in surprising ways, better or worse than expected. Some are artificial, planted purely for visual effect. And as in all other gardens, tending, cultivation, and weeding come with the terrain.”). The Secretary of the Department of Health and Human Services has already determined that the ACA’s Class Act, a long-term care insurance program intended to cover the health care costs associated with many daily activities, is not a viable initiative because of the substantial long-term costs of the program. See Letter of Kathleen Sebelius, Sec’y U.S. Dep’t Health & Human Servs., to Hon. John Boehner, Speaker, U.S. House of Reps. (Oct. 14, 2011), available at <http://www.hhs.gov/secretary/letter10142011.html>; U.S. DEP’T HEALTH &

Congress's pursuit of these access-related goals prevailed over other important policy goals, such as bringing health care costs under control.<sup>54</sup> Although many of the reforms in the ACA, like reforms in earlier efforts, altered physician-patient relationships, hospital-patient relationships, and insurer-insured relationships, the hybrid blend of private ordering/private law and public ordering/public law remains a fundamental characteristic of the American health care system and these relationships. Indeed, these relationships continue to be understood in significant part as a matter of private ordering, even though the ACA redefined many rights and duties in these relationships. Furthermore, the ACA did not establish a general statutory right to health care, although the administration has since promulgated what it calls a "Patient's Bill of Rights," an interim final rule predicated upon several provisions of the ACA related to private health insurance.<sup>55</sup>

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HUMAN SERVS., A REPORT ON THE ACTUARIAL, MARKETING, AND LEGAL ANALYSES OF THE CLASS PROGRAM (2011), available at <http://aspe.hhs.gov/daltcp/reports/2011/class/index.pdf>.

<sup>54</sup> See Theda Skocpol & Vanessa Williamson, *Obama and the Transformation of U.S. Public Policy: The Struggle to Reform Health Care*, 42 ARIZ. ST. L.J. 1202, 1231–32 (2011) (explaining that "[i]n a highly partisan atmosphere, in the midst of a burgeoning economic crisis, and with a smaller majority compared to other Democratic presidents who have pushed through major social reforms, President Obama piloted through a sea of entrenched interests and secured a wide-ranging and remarkably progressive health reform bill that draws resources from the privileged in order to spread access to affordable health insurance to most of the U.S. citizenry"); David Orentlicher, *Cost Containment and the Patient Protection and Affordable Care Act*, 6 F.I.U. L. REV. 67, 67–68 (2010) (observing that, "[d]uring the debate that led to the enactment of the [PPACA], public officials recognized the need to address the problems of both access and cost, but in the end, the Act does far more about increasing access than it does about cutting costs").

<sup>55</sup> See Dep't of the Treasury, Dep't of Labor, & Dep't of Health & Human Servs., Interim Final Rule, Patient Protection and Affordable Care Act: Preexisting Condition Exclusions, Lifetime and Annual Limits, Rescissions, and Patient Protections, 75 Fed. Reg. 37,188 (June 28, 2010). On June 22, 2010, the Departments of Health and Human Services, Labor, and Treasury announced the issuance of "regulations to implement a new Patient's Bill of Rights under the Affordable Care Act," which the departments anticipated would apply to health coverage starting on or after September 23, 2010, six months after the enactment of the ACA. See *Fact Sheet: The Affordable Care Act's New Patient's Bill of Rights*, HEALTHREFORM.GOV (June 22, 2010), [http://healthreform.gov/newsroom/new\\_patients\\_bill\\_of\\_rights.html](http://healthreform.gov/newsroom/new_patients_bill_of_rights.html); see also *Reducing Costs, Protecting Consumers: The Affordable Care Act on the One Year Anniversary of the Patient's Bill of Rights*, HEALTHCARE.GOV (Sept. 23, 2011), <http://www.healthcare.gov/law/resources/reports/patients-bill-of-rights09232011a.pdf>. The Department of Health and Human Services has indicated that the Patient's Bill of Rights provides coverage to individuals with pre-existing conditions, protects patient choice of doctors, keeps young adults covered, ends lifetime limits on coverage, ends pre-existing condition exclusions for children, ends arbitrary withdrawals of insurance coverage, reviews premium increases, helps individuals get the most from their premium dollars, restricts annual dollar limits on coverage, and removes insurance company barriers to emergency services. *Patient's Bill of Rights*, HEALTHCARE.GOV (July 1, 2010), <http://www.healthcare.gov/law/features/rights/bill-of-rights/index.html>. The Patient's Bill of Rights is predicated upon provisions of the ACA that are addressed in this Section of the Article.

### A. Increase of Access and Reduction of Barriers

The ACA sought to increase access to health care and to reduce barriers through a range of initiatives.<sup>56</sup> These initiatives addressed both economic and noneconomic barriers.

#### 1. Economic Barriers

The ACA sought to expand private health insurance coverage by prohibiting insurers from imposing lifetime and annual benefit caps as well as restricting their ability to rescind coverage.<sup>57</sup> It required health insurers that offer dependent coverage to extend that coverage so that parents are able to maintain their adult children on their health insurance until the children reach twenty-six years of age.<sup>58</sup> The ACA required private health insurers to cover the essential health benefits package in their policies,<sup>59</sup> and to cover individuals participating in approved clinical trials.<sup>60</sup> The ACA prohibited private health insurers from discriminating in their premium rates based upon health status,<sup>61</sup> imposing any preexisting condition exclusions,<sup>62</sup> and discriminating in their eligibility standards based upon certain health status-related factors.<sup>63</sup> It also required health insurers that offer health insurance coverage in the individual or group market to accept every employer and individual in the state that applies for health insurance coverage and to renew such coverage at the option of the plan sponsor or individual.<sup>64</sup>

The ACA undertook to promote wellness and make preventive health services more readily available by requiring insurers to provide coverage (and not impose cost sharing requirements) for preventive health services that have received an A or B rating from the United States Preventive

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<sup>56</sup> Initiatives to increase access to health care are found in various titles of the ACA. Most provisions to expand health insurance coverage are located in Titles I and II.

<sup>57</sup> 42 U.S.C.A. §§ 300gg-11 to -12 (West 2003 & Supp. 2011). The ACA restricts the ability of health insurers to rescind the coverage of enrollees by limiting rescissions to circumstances in which a covered individual “has performed an act or practice that constitutes fraud or makes an intentional misrepresentation of material fact as prohibited by the terms of the plan or coverage[.]” such as in the individual’s application for coverage. *Id.* § 300gg-12. Consequently, insurers may not retroactively cancel an individual’s coverage because of an error, mistake, or misstatement on the insurance coverage application.

<sup>58</sup> *Id.* § 300gg-14.

<sup>59</sup> *Id.* § 300gg-6. The essential health benefits package is specified under § 18022.

<sup>60</sup> *Id.* § 300gg-8.

<sup>61</sup> *Id.* § 300gg-1. The new law specifies factors that may be used to vary premium rates, including coverage of an individual or family, rating area, age, and tobacco use. *Id.* § 300gg-1.

<sup>62</sup> *Id.* § 300gg-3.

<sup>63</sup> *Id.* § 300gg-5. The health status-related factors include: health status; medical condition; claims experience; receipt of health care; medical history; genetic information; evidence of insurability; and disability. *Id.* § 300gg-5(a).

<sup>64</sup> *Id.* §§ 300gg-2 & -4.

Services Task Force.<sup>65</sup> Congress sought to increase access to clinical preventive services for medically-underserved children by directing the Secretary of the Department of Health and Human Services (“HHS Secretary”) to award grants for the establishment and operation of school-based health centers.<sup>66</sup> Similarly, it sought to increase access for Medicare and Medicaid beneficiaries by expanding covered preventive services benefits, removing cost-sharing, and building evidence-based incentive programs to prevent chronic diseases.<sup>67</sup>

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<sup>65</sup> *Id.* § 300gg-13. More specifically, the act mandated that group health plans and health insurance issuers offering group or individual health insurance coverage to provide, at a minimum, coverage for the following:

- (1) evidence-based items or services that are currently recommended with a rating of A or B by the United States Preventive Services Task Force;
- (2) immunizations that are currently recommended by the Advisory Committee on Immunization Practices of the Centers for Disease Control and Prevention;
- (3) as to infants, children, and adolescents, evidence-informed preventive care and screenings provided for in the comprehensive guidelines supported by the Health Resources and Services Administration;
- (4) as to women, additional preventive care and screenings not described in paragraph (1) as provided for in the comprehensive guidelines supported by the Health Resources and Services Administration;
- (5) for purposes of breast cancer screening, mammography, and prevention, the current recommendations of the United States Preventive Services Task force are considered the most current, other than those issued in or around November 2009.

*Id.* § 300gg-13(1) to (5). In addition to prohibiting the imposition of cost-sharing requirements for these items or services, the ACA directed that health plans and issuers are not prohibited from providing coverage for services in addition to those recommended by the Task Force. *Id.* The initiative in the ACA to extend health insurance coverage to a wider range of preventive health services is a significant development in the law. As one commentator has noted: “By requiring . . . health plans to provide evidence-based preventive services with no out-of-pocket costs, the ACA transforms the U.S.’s public and private health care financing systems into vehicles for promoting public health.” John Aloysius Cogan, Jr., *The Affordable Care Act’s Preventive Services Mandate: Breaking Down the Barriers to Nationwide Access to Preventive Services*, 39 J.L. MED. & ETHICS 355, 355 (2011).

<sup>66</sup> 42 U.S.C.A. § 280h-4.

<sup>67</sup> ACA § 4103 (codified in scattered sections of 42 U.S.C.) (expanding Medicare coverage of annual wellness visit to include personalized prevention plan services and eliminating cost sharing); *id.* § 4104 (codified in scattered sections of 42 U.S.C.) (removing some coinsurance and deductible requirements related to preventive services in the Medicare program); 42 U.S.C.A. § 1395m (authorizing the HHS Secretary to modify Medicare coverage of preventive service consistent with the recommendations of the United States Preventive Services Task Force and the services covered in the initial preventive physical examination and prohibiting payment for preventive services that have not received a grade of A, B, C, or D); *id.* § 1396d (authorizing state Medicaid programs to provide

The ACA provided for premium tax credits and cost-sharing reductions for income-eligible individuals and families enrolled in qualified health plans in the state exchanges.<sup>68</sup> Furthermore, it called for the immediate creation of two temporary programs to preserve and expand coverage: (1) a high-risk health insurance pool program to provide health insurance coverage for uninsured individuals with preexisting conditions;<sup>69</sup> and (2) an early retiree reinsurance program to provide reimbursement for some of the costs employment-based plans incur in providing coverage to early retirees (who are fifty-five years of age and older but not yet eligible for Medicare) and their eligible spouses, surviving spouses, and dependents.<sup>70</sup>

The ACA also sought to increase access to health care through the Medicaid program and the Children's Health Insurance Program ("CHIP"). The ACA expanded Medicaid eligibility to include all individuals and families not previously eligible who have household incomes that do not exceed 133% of the poverty line,<sup>71</sup> and it required income eligibility to be determined by a new uniform modified-gross-income standard.<sup>72</sup> Medicaid eligibility was also extended to individuals under twenty-six years of age who were formerly in state foster care programs.<sup>73</sup> The ACA extended federal funding for CHIP through fiscal year 2015 to ensure health insurance for poor children under the program.<sup>74</sup>

## 2. Noneconomic Barriers

The ACA addressed noneconomic barriers to health care by

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diagnostic, screening, preventive, and rehabilitative services, including any clinical preventive services with a grade of A or B, adult vaccinations recommended by the Advisory Committee on Immunization Practices, and any medical or remedial services recommended by an authorized practitioner for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level); ACA § 4107 (codified in scattered sections of 42 U.S.C.) (requiring state Medicaid programs to cover comprehensive tobacco cessation services for pregnant women in the program); 42 U.S.C.A. § 1396a (authorizing the HHS Secretary to award grants to states to carry out initiatives to provide incentives to Medicaid beneficiaries to participate in evidence-based, healthy-lifestyle, behavior-modification programs).

<sup>68</sup> 26 U.S.C.A. §280c. In an effort to ensure that individuals have access to therapies, the ACA prohibited the HHS Secretary from promulgating regulations that would have certain limiting effects, including: (1) creating any unreasonable barriers to obtain appropriate medical care; (2) impeding timely access to health care; (3) interfering with patient-provider communications regarding treatment options; (4) restricting provider disclosure of all relevant information to patients; (5) violating informed consent or ethical standards governing health care professionals; or (6) limiting availability of health care treatments. 42 U.S.C.A. § 18115.

<sup>69</sup> 42 U.S.C.A. § 18001.

<sup>70</sup> *Id.* § 18002.

<sup>71</sup> *Id.* § 1396a.

<sup>72</sup> *Id.* § 1396a(e). This same standard is also used to determine eligibility for subsidies for health insurance purchased through the exchanges.

<sup>73</sup> *Id.* § 1396a(a)(10)(A)(i)(IX).

<sup>74</sup> *Id.* § 18031.

reaffirming the application of existing anti-discrimination statutes in health care. The ACA prohibited discrimination on the basis of race, color, or national origin (referencing Title VI of the Civil Rights Act of 1964);<sup>75</sup> sex (referencing Title IX of the Education Amendments of 1972);<sup>76</sup> age (referencing the Age Discrimination Act of 1975);<sup>77</sup> and disability (referencing Section 504 of the Rehabilitation Act).<sup>78</sup> The ACA mandated that no individual may

be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under [Title I of the ACA] (or amendments).<sup>79</sup>

#### B. *Alteration of the Health Care Environment*

Through a number of initiatives, the ACA sought to secure an environment in which individuals can pursue their own goods. The ACA mandated that private health insurers implement effective appeals processes so that enrollees can effectively challenge claims and coverage determinations by private health insurers.<sup>80</sup> It instituted protections to safeguard patient choices of primary care providers and pediatric care providers, ensure coverage of emergency services, and guarantee direct patient access to obstetrical and gynecological care.<sup>81</sup> In another major initiative, the ACA called for the establishment of state-based health insurance exchanges (American Health Benefit Exchanges) that will function as new marketplaces from which individuals and businesses may purchase health insurance from qualified health plans that cover a package of essential health benefits.<sup>82</sup> The ACA also included an array of

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<sup>75</sup> *Id.* § 18116(a).

<sup>76</sup> *Id.*

<sup>77</sup> *Id.*

<sup>78</sup> *Id.*

<sup>79</sup> *Id.* The ACA also directed that no provision of Title I “shall be construed to invalidate or limit the rights, remedies, procedures, or legal standards available to individuals aggrieved” under Titles VI and VII of the Civil Rights Act of 1964, Title IX of the Education Amendments of 1972, Section 504 of the Rehabilitation Act, or the Age Discrimination Act of 1975, or “to supersede State laws that provide additional protections against discrimination on” the basis of race, color, national origin, sex, age, or disability. *Id.* § 18116.

<sup>80</sup> *Id.* § 300gg-19.

<sup>81</sup> *Id.* § 300gg-19a.

<sup>82</sup> *Id.* § 18021. The essential health benefits package includes the following general categories of items and services: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services; prescription drugs; rehabilitative and

initiatives to improve public health systems, increase access to clinical and community preventive services,<sup>83</sup> and enlarge the health care workforce.<sup>84</sup> In the interest of providing consumers with more nutritional information regarding food items purchased at chain restaurants, Congress required such restaurants to provide nutrition labeling on standard menu items.<sup>85</sup>

The ACA initiated a health education and outreach campaign to raise public awareness of health improvement for individuals across the life span.<sup>86</sup> The HHS Secretary was directed to plan and implement a national public-private partnership to spearhead an information dissemination effort that, among other things, describes the importance of utilizing preventive services to promote wellness, reduce health disparities, and mitigate chronic disease; promotes the use of recommended preventive services; encourages healthy behaviors to prevent chronic diseases; and explains the preventive services covered under health plans.<sup>87</sup> Through the Director of the Centers for Disease Control and Prevention (the “CDC Director”), the Secretary is to implement a science-based media campaign on health promotion and disease prevention and to disseminate health promotion and disease prevention information to health care providers.<sup>88</sup> The Secretary is to develop and maintain two Internet websites. The first, which is for health care providers and consumers, is to provide science-based information on guidelines for nutrition, regular exercise, obesity reduction, smoking cessation, and chronic disease prevention.<sup>89</sup> The second, which is for individuals, is to provide a personalized prevention plan tool that incorporates up-to-date scientific evidence regarding disease prevention and enables individuals to determine their risk of developing five leading diseases and obtain personalized suggestions for preventing these diseases.<sup>90</sup>

The ACA directed the HHS Secretary to develop standards to ensure

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habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services. *Id.* § 18022(a)(1)–(b). The act limits cost-sharing with the essential health benefits package. *Id.* § 18022(c). On December 16, 2011, the HHS Secretary released a bulletin announcing its intention to grant states more flexibility in selecting an existing health plan to set the “benchmark” for items and services included in the essential health benefits package. CTR. FOR CONSUMER INFO. AND INS. OVERSIGHT, ESSENTIAL HEALTH BENEFITS BULLETIN (Dec. 16, 2011), *available at* [http://cciio.cms.gov/resources/files/Files2/12162011/essential\\_health\\_benefits\\_bulletin.pdf](http://cciio.cms.gov/resources/files/Files2/12162011/essential_health_benefits_bulletin.pdf).

<sup>83</sup> Title IV of the act includes an array of chronic disease prevention and public health promotion initiatives. *See* ACA §§ 4001–4402 (codified in scattered sections of 42 U.S.C.).

<sup>84</sup> Title V of the act puts forward a range of initiatives to improve and increase the supply of the health care workforce. *See* ACA §§ 5001–5701 (codified in scattered section of 42 U.S.C.).

<sup>85</sup> 21 U.S.C.A. § 343 (West 2003 & Supp. 2011).

<sup>86</sup> 42 U.S.C.A. § 300u-12(a).

<sup>87</sup> *Id.*

<sup>88</sup> *Id.* §§ 300u-12(c), (e).

<sup>89</sup> *Id.* § 300u-12(d).

<sup>90</sup> *Id.* § 300u-12(f).



that private health insurers provide understandable summaries of benefits and coverage for enrollees.<sup>91</sup> It required the Secretary to award grants to states to establish or expand offices of health insurance consumer assistance or an ombudsman program to assist consumers with the filing of complaints and appeals, and to respond to consumer complaints regarding health insurance coverage.<sup>92</sup> It also directed the HHS Secretary (in conjunction with states) to establish a process for annual reviews of unreasonable increases in premiums for health insurance,<sup>93</sup> and to carry out a grant program to assist states.<sup>94</sup> Furthermore, it assigned the Secretary the responsibility of establishing an Internet portal through which individuals and small businesses can obtain information and identify affordable health insurance coverage options.<sup>95</sup>

#### IV. TWO BOUNDARY AREAS

The public policy goals of increasing access, reducing barriers, and securing an environment in which individuals can seek their own goods are worthy goals that the states and the federal government have rightly pursued for decades. These three policy goals and the various state and federal efforts to advance these goals have been motivated by an array of important, patient-centered concerns, such as the autonomy of the patient, the decisional empowerment of the patient, the control of patient-related information by the patient, the protection of the patient-consumer, and the protection of the insured/subscriber-consumer. The ACA built upon earlier state and federal efforts, and it took additional steps toward the achievement of these goals. Furthermore, the initiatives in the ACA added to the complex hybrid blend of private and public ordering that characterizes the American health care system.

Nevertheless, even as we as a people contemplate the successes and failures of past efforts to increase access, evaluate the need for additional state and federal legislation, and continue to pursue these goals, we should revisit some of the other important considerations, values, and principles (such as those involving voluntariness, consent, and liberty in the physician-patient relationship, as well as the nature of medical practice and professional medical judgment) that have faded into the background and have been obscured by our focus on increasing access, safeguarding patient autonomy, empowering patients, and protecting patients and subscribers as consumers. These considerations, values, and principles more profoundly informed our understanding of the physician-patient relationship, the

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<sup>91</sup> *Id.* § 300gg-15.

<sup>92</sup> *Id.* § 300gg-93.

<sup>93</sup> *Id.* § 300gg-94.

<sup>94</sup> *Id.*

<sup>95</sup> *Id.* § 18003.

hospital-patient relationship, and the insurer-insured relationship when these relationships were understood more simply as a matter of private ordering governed by private law. However, these considerations, values, and principles remain relevant and may help us to evaluate some additional reconciliation work that is necessary.

One way to approach the revisitation of these other important considerations, values, and principles is to ponder whether there are some real boundaries that legitimately define limitations on access to health care. Two boundary areas are: (1) the professional provider's judgment about medical necessity, effectiveness, and appropriateness; and (2) the provider's judgment on matters of conscience in the provision of care. Both of these boundary areas are implicated by the ACA and are part of the post-comprehensive health care reform debate, and both warrant further reflection and discussion.<sup>96</sup>

*A. Boundary Area One: The Professional Provider's Judgment Regarding Medical Necessity, Effectiveness, and Appropriateness*

This boundary area raises at least two key questions: (1) what items and services should patients (and subscribers/insureds) be able to receive (and have them covered by health insurance); and (2) who should decide whether they receive them? This boundary area recognizes the importance of preserving, in the therapeutic relationship, decision-making authority regarding the necessity, effectiveness, and appropriateness of medical and preventive care. It brings into focus concerns regarding the locus of decision making, the fundamental values governing medical practice, the medical judgment of the professional provider, and the moral commitment of the medical professional to the patient.

*1. Medical Care, Professional Judgment, Coverage Determinations, and Decisional Locus*

Traditionally, the professional judgment of the patient's physician was decisive in determining what items and services were medically necessary, effective, and appropriate, as well as what items and services patients would receive. Thus, during the era when the physician-patient relationship was understood primarily as a matter of private ordering governed by private law, the physician maintained decisional authority and controlled treatment decisions. However, the doctrine of informed

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<sup>96</sup> This Article proposes that there are boundaries that, unlike certain barriers such as race and national origin, legitimately limit access to health care. Rather than advocating for a new paternalism in medicine or suggesting that the professional's judgment should be unassailable, this Article argues that, in our efforts to increase access, reduce barriers, and secure an environment in which individuals can pursue their own goods, we must work to reconcile these public policy goals and to accommodate countervailing considerations, values, and principles.

consent, predicated upon principles of patient autonomy, human dignity, personal inviolability, and bodily integrity brought about a significant adjustment in decisional authority in the physician-patient relationship.<sup>97</sup> Consequently, patients obtained control over treatment decision-making.

With the passage of time, the locus of health care decision-making was further adjusted. For instance, nearly half a century ago, as the growth of health care costs became a concern to third-party payers, private health plans began to include vaguely worded exclusions and other restrictions in their policies to better manage cost.<sup>98</sup> Accordingly, plans excluded “experimental,” “investigational,” “cosmetic,” and “convenience” services, and they restricted coverage to “medically necessary” services.<sup>99</sup> Based upon these exclusions and restrictions, health insurers increasingly conducted retrospective reviews to ensure the appropriateness of treatments and services provided. Accordingly, health insurance plans came to defer less to the judgment of physicians, whom insurers believed were responsible for the dramatic rise in health care costs based upon their utilization of high-cost technology and their provision of in-patient services.<sup>100</sup> Similarly, in the managed care context, insurers employed mechanisms such as preauthorization, selective contracting with providers, and provider financial incentives to control costs and reduce overutilization of services by providers.<sup>101</sup> These exclusions and managed care mechanisms, however, played a part in shifting decisional authority from the patient and the provider to the health insurer.

Several public controversies have arisen around this boundary that have highlighted the tension between locating decisional authority with physicians caring for patients in individual cases and with organizations and agencies considering general data regarding treatments and services.

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<sup>97</sup> See *supra* notes 46–50 and accompanying text.

<sup>98</sup> William M. Sage, *Managed Care's Crimea: Medical Necessity, Therapeutic Benefit, and the Goals of Administrative Process in Health Insurance*, 53 DUKE L.J. 597, 605 (2003).

<sup>99</sup> *Id.* at 605–06.

<sup>100</sup> *Id.* One commentator has noted the early judicial antipathy for such exclusions and denials of coverage:

[I]n rare instances where insurers did initially deny coverage for unnecessary procedures, they were frequently rebuffed in that endeavor by courts receptive to patient and physician claims of authority. Courts steadfastly embraced therapeutic individualism in such rulings, explaining for instance that “[o]nly the treating physician can determine what the appropriate treatment should be” and that “[a]ny other standard would involve intolerable second-guessing” by third-party payors.

Theodore W. Ruger, *Plural Constitutionalism and the Pathologies of American Health Care*, 120 YALE L.J. ONLINE 347, 362 (2011) (quoting *Mount Sinai Hosp. v. Zorek*, 271 N.Y.S.2d 1012, 1016 (Civ. Ct. 1966)).

<sup>101</sup> Sage, *supra* note 98, at 606.

These controversies have also highlighted some access-to-care implications of shifts in the decisional locus. From the late 1980s to the early 2000s, controversy surrounded the refusal of insurance companies to cover high dose chemotherapy with autologous bone marrow transplant deemed necessary by many physicians as a treatment for women suffering from breast cancer.<sup>102</sup> Some insurers responded to the controversy and litigation by covering the treatment, and some legislatures stepped in and mandated coverage.<sup>103</sup> More recently, in 2009, the United States Preventive Services Task Force changed its recommendations regarding routine screening mammography in women between the ages of forty and forty-nine years. In response to a strong public reaction, the Obama administration highlighted the non-binding nature of task force recommendations as to physicians and insurers, and Congress directly addressed the task force recommendation in the ACA.<sup>104</sup> This same task force has recommended against screening for prostate cancer in men who are seventy-five years of age or older.<sup>105</sup>

Two initiatives in the ACA bring this first boundary area into the foreground: (1) the patient-centered outcomes research initiative; and (2) the prevention and wellness initiative.<sup>106</sup> In the patient-centered outcomes research initiative,<sup>107</sup> Congress authorized the establishment of a nongovernmental, nonprofit, tax-exempt Patient-Centered Outcomes

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<sup>102</sup> See, e.g., *Harris v. Mut. of Omaha Cos.*, 992 F.2d 706 (7th Cir. 1993) (affirming trial court's denial of injunctive relief against health insurer's denial of coverage); *Lubeznik v. HealthChicago, Inc.*, 644 N.E.2d 777 (Ill. App. Ct. 1994) (affirming trial court's award of injunctive relief against health insurer requiring pre-certifications for certain medical treatment); see also Michelle M. Mello & Troyen A. Brennan, *The Controversy over High-Dose Chemotherapy with Autologous Bone Marrow Transplant for Breast Cancer*, 20 HEALTH AFF. 101 (2001) (discussing results of five major clinical studies, and cautioning against allowing politics to overwhelm science). This treatment ultimately was proven to be no more effective for the treatment of breast cancer than standard chemotherapy. E. Haavi Morreim, *A Dose of Our Own Medicine: Alternative Medicine, Conventional Medicine, and the Standards of Science*, 31 J.L. MED. & ETHICS 222, 224 & n.23 (2003).

<sup>103</sup> See Morreim, *supra* note 102, at 224.

<sup>104</sup> See Paul Bernstein, *Prevention of Illness*, 12 MARQ. ELDER'S ADVISOR 157, 158–59 (2010); see also *supra* note 65.

<sup>105</sup> *Id.* at 170–74; *Screening for Prostate Cancer*, U.S. PREVENTIVE SERVICES TASK FORCE available at <http://www.uspreventiveservicestaskforce.org/uspstf/uspstfprca.htm> (last visited Apr. 9, 2012).

<sup>106</sup> See generally Michael J. DeBoer, *Medicare Coverage Policy and Decision Making, Preventive Services, and Comparative Effectiveness Research Before and After the Affordable Care Act*, 7 J. HEALTH & BIOMED. L. 492, 534–40, 557–65 (2012) (discussing the patient-centered outcomes research and preventive services initiatives in the ACA, especially as they affect the Medicare program).

<sup>107</sup> Subtitle D (Patient-Centered Outcomes Research) of Title VI (Transparency and Program Integrity) of the PPACA, which included two sections, § 6301 (Patient-Centered Outcomes Research) and § 6302 (Federal Coordinating Council for Comparative Effectiveness Research), put forward the patient-centered outcomes initiative. 42 U.S.C.A. §§ 1320e & 299b-8 (West 2003 & Supp. 2011). It also established the Patient-Centered Outcomes Research Trust Fund in the Treasury of the United States and authorized appropriations. *Id.* § 1320e(e)(1).

Research Institute ("PCOR Institute") to develop and fund comparative effectiveness research.<sup>108</sup> Congress intended the PCOR Institute to play a central role in generating, gathering, synthesizing, and disseminating evidence regarding the effectiveness of medical interventions "to assist patients, clinicians, purchasers, and policy-makers in making informed health decisions."<sup>109</sup> The ACA, however, limited the authority of the PCOR Institute to mandate health insurance coverage or reimbursement policy. It directed that the provisions of the ACA establishing the patient-centered outcomes research initiative "shall [not] be construed . . . to permit the [PCOR] Institute to mandate coverage, reimbursement, or other policies for any public or private payer."<sup>110</sup> Furthermore, the ACA prohibited the PCOR Institute from "develop[ing] or employ[ing] a dollars-per-quality adjusted life year (or similar measure that discounts the value of a life because of an individual's disability) as a threshold to establish what type of health care is cost effective or recommended."<sup>111</sup>

In the prevention and wellness initiative, Congress sought to advance prevention, wellness, and health promotion practices through a range of programs.<sup>112</sup> In addition to provisions designed to expand health insurance

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<sup>108</sup> 42 U.S.C.A. §§ 501(1)(4) & 1320e(b)(1). Comparative clinical effectiveness research is "research evaluating and comparing health outcomes and the clinical effectiveness, risks, and benefits of 2 or more medical treatments, services, and items." *Id.* § 1320e(a)(2)(A).

<sup>109</sup> *Id.* § 1320e(c). According to the ACA, the PCOR Institute is to achieve its purpose of getting the best available information to those involved in making health decisions by advancing, first, "the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed through research and evidence synthesis that considers variations in patient subpopulations" and, second, "the dissemination of research findings with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments, services, and items . . . ." *Id.* The term "medical treatments, services, and items" encompasses "health care interventions, protocols for treatment, care management, and delivery, procedures, medical devices, diagnostic tools, pharmaceuticals (including drugs and biologicals), integrative health practices, and any other strategies or items being used in the treatment, management, and diagnosis of, or prevention of illness or injury in, individuals[.]" and thus Congress intended a broad scope for this research initiative. *Id.* § 1320e(a)(2)(B).

<sup>110</sup> *Id.* § 1320e(j)(1)(A). Additionally, when the PCOR Institute makes its research findings available to clinicians, patients, and the general public, the institute must ensure that research findings "do not include practice guidelines, coverage recommendations, payment, or policy recommendations . . . ." *Id.* § 1320e(d)(8)(A)(iv).

<sup>111</sup> *Id.* § 1320e-1(e).

<sup>112</sup> Title IV of the ACA (Prevention of Chronic Disease and Improving Public Health) includes most of components of the preventive services initiative. ACA §§ 4001-4402 (codified in scattered sections of 42 U.S.C.). For discussion of additional Title IV components of the prevention and wellness initiative, see *supra* Section III.B. In Title I of the ACA (Quality, Affordable Health Care for All Americans), Congress placed the provision requiring health insurance plans to cover preventive services and immunizations recommended by the Preventive Services Task Force and the Centers for Disease Control and Prevention and certain preventive services as recommended by the Health Resources and Services Administration. 42 U.S.C.A. § 300gg-11. One commentator has observed that "[i]nside and outside Title IV are far-reaching initiatives to provide nearly every American with access to evidence-based preventive health services as part of their insurance coverage and without cost

coverage of preventive services,<sup>113</sup> the ACA required the Director of the Agency for Healthcare Research and Quality to convene an independent Preventive Services Task Force to review the scientific evidence related to the effectiveness, appropriateness, and cost-effectiveness of clinical preventive services for the purpose of developing recommendations for the health care community and updating existing clinical preventive recommendations.<sup>114</sup> In making its recommendations, the task force is to consider clinical preventive best practice recommendations from a range of public agencies and private agencies and entities.<sup>115</sup> Additionally, the ACA directed the Preventive Services Task Force to coordinate its work with the independent Community Preventive Services Task Force—which

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sharing.” MCDONOUGH, *supra* note 53, at 188. Several prevention and wellness programs in Title IV should be also noted. The ACA called for the President to establish the National Prevention, Health Promotion and Public Health Council within the Department of Health and Human Services as an interagency council to lead the federal effort in prevention, wellness, and health promotion practices, the public health system, and integrative health care. 42 U.S.C.A. §§ 300u-10(a) & (d)(1). The council, which is to be composed of the heads of various federal departments and agencies, *id.* §§ 300u-10(b) & (c)(1) to (13), has various duties: developing a national strategy for improving health status and reducing the incidence of preventable illness and disability; making recommendations regarding pressing health issues and policy changes necessary to achieve wellness, health promotion, and public health goals; proposing evidence-based models, policies, and innovative approaches for promoting transformative models of prevention, integrative health, and public health; and establishing processes for public input, *id.* § 300u-10(d)(2) to (6). The ACA also called upon the President to establish the Advisory Group on Prevention, Health Promotion, and Integrative and Public Health, which is to be composed of non-federal members from licensed health professions, to develop policy and program recommendations, and to advise the council on lifestyle-based chronic disease prevention and management, integrative health care practices, and health promotion. *Id.* §§ 300u-10(f)(1) & (f)(3). The ACA established the Prevention and Public Health Fund, which is to be administered by the HHS Secretary, to invest in prevention and public health programs, promote health, and restrain the growth rate of both private and public sector health care costs, *id.* § 300u-11(a), and it authorized appropriations to this fund, *id.* § 300u-11(b).

<sup>113</sup> See *supra* Section III.A.

<sup>114</sup> 42 U.S.C.A. § 299b-4(a)(1). The members of the task force are to be independent and, to the extent practicable, not subject to political pressure. *Id.* § 299b-4(a)(6). Recommendations are to be published in the *Guide to Clinical Preventive Services* for individuals and organizations delivering clinical services. *Id.* § 299b-4(a)(1). The list of individuals and organizations includes primary care professionals, health care systems, professional societies, employers, community organizations, non-profit organizations, Congress and other policy-makers, governmental public health agencies, health care quality organizations, and organizations developing national health objectives.

<sup>115</sup> *Id.* § 299b-4(a)(2). These include the Agency for Healthcare Research and Quality, the National Institutes of Health, the Centers for Disease Control and Prevention, the Institute of Medicine, specialty medical associations, patient groups, and scientific societies. *Id.* § 299b-4(a)(1). The ACA assigned a number of duties to the task force: (1) developing additional topic areas for new recommendations and interventions related to those topic areas; (2) reviewing interventions and updating recommendations related to existing topic areas at least once during every five-year period; (3) improving integration with federal government health objectives and related target setting for health improvement; (4) enhancing the dissemination of recommendations; and (5) providing technical assistance to those health care professionals, agencies, and organizations that request help in implementing the recommendations. *Id.*

was to be convened by the CDC Director<sup>116</sup>—and with the Advisory Committee on Immunization Practices to examine how the recommendations of each task force interact at the clinic-community nexus.<sup>117</sup>

Congress in these two initiatives sought to increase access, reduce barriers, and secure an environment in which individuals can pursue their own goods by promoting the development and dissemination of better information for patients and providers making health decisions and extending health insurance coverage to additional preventive services. However, these two initiatives also threaten further encroachment upon the physician's judgment about medical necessity, effectiveness, and appropriateness. The work of the PCOR Institute and the Preventive Services Task Force will add to and likely accelerate the decades-long trend to shift the decisional locus in medical necessity, effectiveness, and appropriateness determinations away from physicians treating particular patients and to organizations and agencies making effectiveness determinations based on generalized knowledge. Consequently, the patient-outcomes research findings of the PCOR Institute and the recommendations of the Preventive Services Task Force—especially as they are translated into, and otherwise impact the provision of, clinical services and determinations regarding insurance coverage—will fuel controversy and engender mistrust.

## 2. *Decisional Locus, the Practice of Medicine, and the Therapeutic Relationship*

The progressive shift of the decisional locus in medical necessity, effectiveness, and appropriateness determinations away from the professional provider and patient undercuts a number of important values in medicine. At one time, one of the critical moral and legal issues in the physician-patient relationship was the proper allocation of decision-making authority between the patient and the physician, and the doctrine of informed consent developed to ensure patient control. Now, however, an increasingly pressing issue is the allocation of decision-making authority between the two parties to the therapeutic relationship and the remote individuals, organizations, and agencies that make effectiveness determinations and issue coverage policy. To borrow some terminology

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<sup>116</sup> *Id.* § 280g-10(a). Congress intended that the independent Community Preventive Services Task Force would review scientific evidence related to the effectiveness, appropriateness, and cost-effectiveness of community preventive interventions for the purpose of developing recommendations, and under the ACA, the term "community prevention services" includes any policies, programs, processes, or activities designed to affect or otherwise affecting health at the population level. *Id.* These recommendations are to be published in the *Guide to Community Preventive Services* for individuals and organizations delivering population-based services. *Id.*

<sup>117</sup> *Id.* §§ 280g-10(a), 299b-4(a)(1).

from administrative law, physicians who treat individual patients based upon case-specific information perform a “quasi-adjudicative” function, but remotely located individuals, organizations, and agencies that make determinations based upon general knowledge perform a “quasi-legislative” function.<sup>118</sup> These functions and the related activities and decision-making processes are fundamentally different in nature. Consequently, shifting the location of decision-making away from physicians treating particular patients and providing tailored care based upon the specific facts and circumstances of each patient’s case to more remote individuals, organizations, and agencies that make medical necessity, effectiveness, and appropriateness determinations based on generalized knowledge and facts is a significant relocation.<sup>119</sup>

The practice of medicine involves more than the use of scientific knowledge and medical skill and technique. It is also an art that draws upon clinical experience and requires judgment regarding the appropriate diagnosis and treatment.<sup>120</sup> Additionally, physicians are members of an organized, autonomous, self-regulating profession that is distinguished by its specialized education and training, standards of ethics, independence of judgment, duties of confidentiality, and fiduciary duties. Furthermore, the physician-patient relationship is established upon a moral commitment.<sup>121</sup>

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<sup>118</sup> In administrative law parlance, this shift represents a move from adjudicative activity and decision-making, which is oriented to specific individuals based upon past events and circumstances, to legislative activity and decision-making, which is oriented to larger groups based upon facts pertaining to the group affected. Eleanor D. Kinney, *Protecting Consumers and Providers Under Health Reform: An Overview of the Major Administrative Law Issues*, 5 HEALTH MATRIX 83, 90 (1995); see also Kenneth Culp Davis, *An Approach to Problems of Evidence in the Administrative Process*, 55 HARV. L. REV. 364, 402 (1942) (observing that “[w]hen [a court] finds facts concerning immediate parties—what the parties did, what the circumstances were, what the background conditions were—the [court] is performing an adjudicative function, and the facts may conveniently be called adjudicative facts”); FED. R. EVID. 201 advisory committee’s note (“Adjudicative facts are simply the facts of the particular case. Legislative facts, on the other hand, are those which have relevance to legal reasoning and the lawmaking process, whether in the formulation of a legal principle or ruling by a judge or court or in the enactment of a legislative body.”). Although physicians apply generalized knowledge in individual cases, they apply that general knowledge to the individual patient and her specific needs and circumstances based upon case-specific information.

<sup>119</sup> The same can be said for practice guidelines. See Judith E. Orie, *Economic Credentialing: Bottom-Line Medical Care*, 36 DUQ. L. REV. 437, 444–45 (1998) (observing that “[m]ost of the practice guidelines, however, rely on a panel of experts who merely extrapolate data from studies appearing in the medical literature. Typically, however, these experts are far removed from the actual physician-patient encounter.”).

<sup>120</sup> 63 PA. CONS. STAT. § 422.2 (2010) (“‘Medicine and surgery’ [are] [t]he art and science of which the objectives are the cure of diseases and the preservation of the health of man, including the practice of the healing art with or without drugs . . . .”); Orie, *supra* note 119, at 444 (stating that “[m]edical practice and patient care is indeed a science, but the fact remains that the practice of medicine is an art, combining scientific knowledge with the clinical experience of the physician”).

<sup>121</sup> See *Preamble: Principles of Medical Ethics*, AM. MED. ASS’N, available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page?> (“The medical profession has long subscribed to a body of ethical statements developed



In their care for patients, physicians are guided by various moral principles, including beneficence, nonmaleficence, autonomy, and justice, and their conduct is governed by professional, moral, and legal duties. In their care for their patients, physicians owe a duty to do good, to help their patients when they are in need, and to provide for their benefit (beneficence). Physicians also owe their patients a duty to avoid causing them harm (nonmaleficence). Additionally, physicians must respect their patients as persons and honor their decision-making capacities (autonomy), and they must treat patients fairly and give them their due (justice).<sup>122</sup> These moral principles and duties have a long history that extends back to an ancient professional moral code, the Hippocratic Oath, that was used and adapted by professionals in the Christian, Jewish, and Islamic faith traditions, and that has informed medical ethics for millennia.<sup>123</sup>

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primarily for the benefit of the patient. As a member of this profession, a physician must recognize responsibility to patients first and foremost, as well as to society, to other health professionals, and to self.”).

<sup>122</sup> See BEAUCHAMP & CHILDRESS, *supra* note 52, at 12; THOMAS S. BODENHEIMER & KEVIN GRUMBACH, *UNDERSTANDING HEALTH POLICY: A CLINICAL APPROACH* 147–49 (5th ed. 2009); see also STANLEY HAUERWAS, *SUFFERING PRESENCE: THEOLOGICAL REFLECTIONS ON MEDICINE, THE MENTALLY HANDICAPPED, AND THE CHURCH* 4 (1986) (observing that “medicine [is] first and foremost a moral practice constituted by intrinsic moral convictions that are operative even if not explicitly acknowledged”).

<sup>123</sup> The Hippocratic Oath states in relevant part:

I will apply dietetic measure for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice. I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect. Similarly I will not give a woman an abortive remedy. In purity and in holiness I will guard my life and my art.

I will not use the knife, not even on sufferers from stone, but will withdraw in favor of such men as are engaged in this work.

Whatever houses I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular of sexual relations with both female and male persons, be they free or slaves.

What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about.

The Hippocratic Oath (transl. by Ludwig Edestein), available at <http://www.hsl.virginia.edu/historical/artifacts/antiqua/hippocrates.cfm>. The Hippocratic oath originated in the ancient world of the Greek pantheon and Greek mythology, but it was adopted by the Christian tradition early in its history and was later adopted in Jewish and Muslim medicine. NIGEL M. DE S. CAMERON, *THE NEW MEDICINE: LIFE AND DEATH AFTER HIPPOCRATES* 41–44 (1991); Leigh N.B. Chipman, *The Professional Ethics of Medieval Pharmacists in the Islamic World*, 21 *MED. & L.* 321, 323–25 (2002) (discussing the roots of medical ethics); Danuta Mendelson, *Historical Evolution and Modern Implications of Concepts of Consent to, and Refusal of, Medical Treatment in the Law of Trespass*, 17 *J. LEGAL MED.* 1, 14–15 (1996) (discussing the persistence of Hippocratic ideas through the medieval period).

The significance of the relational bond between the patient and the physician should not be diminished or overlooked. In an era of practice guidelines, national and local coverage determinations, comparative effectiveness research, task force recommendations, cost controls, and other means of bureaucratic decision-making,<sup>124</sup> the case-specific judgment of a professional who owes her patient fidelity and looks out for her patient's best interests remains an important value. Additionally, this shift in decisional locus from the patient and her physician to individual, organizational, and agency decision-makers threatens to undermine the patient-centered moral and legal developments of the last century by removing the concerns of individual patients and the facts of specific cases from the critical decision-making processes. Furthermore, it seems unlikely that the moral commitment of the physician to the well-being of the individual patient can be matched or replicated in the more remote decision-making processes.

Because the judgments of the treating physicians regarding the medical necessity, effectiveness, and appropriateness of items and services are critically important to safeguard the interests of patients and because the determinations of remote health care decision-makers are unlikely to adequately protect the interests of individual patients, additional reconciliation work is necessary to preserve some of the considerations, values, and principles that have been obscured by our pursuit of access-increasing, barrier-reducing, and environment-altering public policy goals. In this reconciliation work, we should be careful to observe this boundary area and be mindful of the importance of preserving decisional authority in the physician-patient relationship.

*B. Boundary Area Two: The Provider's Judgment on Matters of Conscience in the Provision of Care*

This boundary raises at least one key question: Should access to health care require a provider that is morally opposed to providing certain items and services to provide patients with those items and services? Although increasing access to health care is a worthy policy goal, this boundary area recognizes that increased access to care should not render patients (and subscribers/insureds) entitled to obtain items and services from any provider they desire, especially from providers opposed to providing certain items and services based upon moral objections. This boundary

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<sup>124</sup> See Mark Siegler, *The Progression of Medicine: From Physician Paternalism to Patient Autonomy to Bureaucratic Parsimony*, 145 ARCHIVES OF INTERNAL MED. 713, 713 (1985) (describing fundamental changes in the understanding of medical practice and the physician-patient relationship from a personal encounter between a trusted professional and a patient to "an impersonal encounter between two isolated and autonomous persons—the patient and the physician—whose individual interests were to be rigorously protected").

area brings into focus concerns regarding the conscience, liberty, autonomy, and integrity of individual and institutional providers.<sup>125</sup>

### *1. Recent Regulatory Developments Regarding Health Care Conscience Protection*

Regulatory developments over the last four years have highlighted concern relative to this boundary area. On December 19, 2008, in its final days, the Bush administration promulgated a rule to clarify federal health care conscience protection statutes.<sup>126</sup> These federal statutes prohibit recipients of certain federal funds from coercing individuals in the health care industry into participating in actions they find religiously or morally objectionable.<sup>127</sup> The Bush administration's rule defined key terms, required written certification by certain recipients that they comply with the statutes, and assigned responsibility for complaint handling and investigation.<sup>128</sup> On March 10, 2009, less than two months after taking office, the Obama administration announced that it would review the Bush administration's rule, reevaluate the necessity for regulations implementing the federal health care conscience protection statutes, and proposed a rule rescinding in its entirety the earlier administration's rule.<sup>129</sup>

In late 2009 and early 2010, the ACA was enacted against this background of evolving rules interpreting and implementing the federal health care conscience protection statutes. Then, on February 18, 2011, nearly one year after President Obama signed the ACA into law, the Obama administration rescinded, in part, and revised the Bush administration's rule.<sup>130</sup> In the revised rule, HHS indicated its support for clear and strong conscience protections for providers opposed to abortions. It retained the part of the Bush administration's rule that established an enforcement process, rescinded parts that were, in the Secretary's view,

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<sup>125</sup> Conscience refers to "the moral obligations or duties of conduct and action that are perceived by a person or a community." JOHN T. NOONAN, JR. & EDWARD MCGLYNN GAFFNEY, JR., *RELIGIOUS FREEDOM: HISTORY, CASES, AND OTHER MATERIALS ON THE INTERACTION OF RELIGION AND GOVERNMENT* 1395 (3d ed. 2011).

<sup>126</sup> Dep't of Health & Human Servs., *Ensuring That Department of Health and Human Services Funds Do Not Support Coercive or Discriminatory Policies or Practices in Violation of Federal Law*, 73 Fed. Reg. 78,072 (Dec. 19, 2008) (previously codified at 45 C.F.R. pt. 88). The rule, which went into effect on January 20, 2009, clarified the following federal statutes: the Church Amendments, 42 U.S.C. § 300a-7; the Coats Amendment, Section 245 of the Public Health Service Act, 42 U.S.C. § 238n; and the Weldon Amendment, Consolidated Appropriations Act of 2008, Pub. L. No. 110-161, § 508d, 121 Stat. 1844, 2209.

<sup>127</sup> 73 Fed. Reg. at 78,072.

<sup>128</sup> *Id.*

<sup>129</sup> See Dep't of Health & Human Servs., *Rescission of the Regulation Entitled "Ensuring That Department of Health and Human Services Funds Do Not Support Coercive or Discriminatory Policies or Practices in Violation of Federal Law,"* 74 Fed. Reg. 10,207 (Mar. 10, 2009).

<sup>130</sup> Dep't of Health & Human Servs., *Regulation for the Enforcement of Federal Health Care Provider Conscience Protection Laws*, 76 Fed. Reg. 9968 (Feb. 23, 2011).

unclear or overbroad in scope, and explained that its revised rule did not alter the underlying federal statutes.<sup>131</sup> The initiatives in the ACA that increase access to care are likely to step-up encroachments into this boundary area as a growing number of patients seek items and services, including from providers who object for moral reasons to providing certain items and services.

## 2. *Conscience and Individual and Institutional Health Care Providers*

This boundary area is a matter of concern for both individual and institutional providers.<sup>132</sup> In our society, which has valued personal dignity and individual freedom, we generally do not require people to do those things that they believe are harmful and morally objectionable or that they believe would violate their personal and professional integrity. In other words, we generally do not require individuals or institutions to violate their core values.

With individual providers, a health care professional (such as a physician, a nurse, or a pharmacist) may determine that she cannot provide certain items or services because the course of action would violate her core moral understanding and values.<sup>133</sup> As a member of a health care profession, the professional provider has publicly identified with a medical profession,<sup>134</sup> which might be understood as “an account of medical care that delimits what [the profession] take[s] to be within and without the practice to which [the professionals] commit themselves. . . . [T]his account includes their conceptions of themselves as medical practitioners

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<sup>131</sup> *Id.* at 9969.

<sup>132</sup> The ACA has mandated that most health insurance plans cover certain preventive services (including contraception) without charging a copayment or deductible. See *supra* Section III.A. HHS has promulgated a rule regarding coverage of preventive services by health insurance plans and providing an exemption for certain religious employers where contraceptive services are concerned. See Dep’t of the Treasury, Dep’t of Labor & Dep’t of Health & Human Servs., Group Health Plans and Health Insurance Issuers Relating to Coverage of Preventive Services Under the Patient Protection and Affordable Care Act, 77 Fed. Reg. 8725 (Feb. 15, 2012). Although this ACA mandate and the Obama administration’s rule exempting certain religious organizations from paying their health insurers to cover services they believe are morally objectionable raise conscience-related concerns, HHS’s rule is beyond the scope of this Article.

<sup>133</sup> Principle VI of the AMA’s *Principles of Medical Ethics* states that a “physician shall, in the provision of appropriate care, except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical care.” *Principles of Medical Ethics*, AM. MED. ASS’N, available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page?> (last visited Apr. 9, 2012).

<sup>134</sup> The AMA’s *Code of Medical Ethics* and *Principles of Medical Ethics* are publicly accessible, and they were promulgated to guide the conduct of physician-members of the medical profession and “define the essentials of honorable behavior for physicians.” *Code of Medical Ethics*, AM. MED. ASS’N, available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page?> (last visited Apr. 9, 2012).

and what constitutes a patient, a disease, health, and medical therapy.”<sup>135</sup> So understood, a health care profession is independent of society and government, and its evaluation and resolution of both moral and ethical issues are separate from what the law may require, what society may permit, and what a patient might request.<sup>136</sup> This understanding is reflected, at least in part, in the AMA’s explanation of the medical profession’s view regarding the relationship between law and ethics:

Ethical values and legal principles are usually closely related, but ethical obligations typically exceed legal duties. In some cases, the law mandates unethical conduct. In general, when physicians believe a law is unjust, they should work to change the law. In exceptional circumstances of unjust laws, ethical responsibilities should supersede legal obligations.<sup>137</sup>

Additionally, the health care professions are concerned with more than medical scientific knowledge and technical skills; they must also be mindful of the good that professionals seek and the bad that they seek to avoid.<sup>138</sup>

Another way to conceive of this is that a health care professional may conclude that, notwithstanding a sincere desire to serve a patient and honor a patient’s request (autonomy), providing certain items or services would violate the professional’s sense of doing good (beneficence), not doing harm (nonmaleficence), and giving the patient what is due (justice). That is, the professional would not be acting in accordance with her values and judgment or her belief as to the best interests of the patient, and providing such items or services would compromise her personal and professional integrity.<sup>139</sup> In invoking conscientious objection, the professional’s claim,

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<sup>135</sup> T.A. Cavanaugh, *Professional Conscientious Objection in Medicine with Attention to Referral*, 9 AVE MARIA L. REV. 189, 189–90 (2010).

<sup>136</sup> See *id.* at 190 (“This account understands a profession to have an independent character autonomous from what law permits and society accepts.”).

<sup>137</sup> *Code of Medical Ethics, Opinion 1.02—The Relation of Law and Ethics*, AM. MED. ASS’N, available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion102.page?> (last visited Apr. 9, 2012).

<sup>138</sup> Cavanaugh, *supra* note 135, at 190.

<sup>139</sup> See Thaddeus Mason Pope, *Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment*, 75 TENN. L. REV. 1, 15–16 (2007) (observing that “[t]he medical profession is a self-governing one with its own standards of professional practice. The integrity of the medical profession is an important societal interest that must be balanced against patient autonomy. Indeed, patient autonomy has never been construed as requiring a health professional to provide a particular type of treatment. Since the medical profession determines the goals and values of medicine, it can judge certain requests as inconsistent with those goals and values.”) (footnotes and quotation marks omitted).

then, is that, despite a moral and legal commitment to the patient, the professional should have the liberty to refuse to provide certain items or services because providing such items or services would violate her conscience (i.e., her professional judgment regarding immoral practices and conduct in which she cannot participate).<sup>140</sup> In this sense, the professional's objection is informed by a professional judgment, rather than a strictly religious or private belief.

In such a situation, the professional's primary concern is not with judging the patient's intention or conduct, but with the professional's own conduct, participation, and cooperation. When a patient has asked the professional provider to participate in or facilitate a course of action, the professional should be at liberty to act in a way that is consistent with her own professional judgment that participating in or facilitating certain action is morally objectionable for her and would undermine her personal and professional integrity.

With institutional providers, especially those that are affiliated with a religious tradition or are owned by a church, the institution (and the sponsoring organization, which may include clergy who are members of another profession) may determine that certain items or services are morally objectionable and that such items or services should not be provided within the institution. Like individual professional providers, institutional providers should be at liberty to act in a manner consistent with their values and purposes; this is a matter of institutional integrity. Institutions are created by individuals who are committed to pursuing a particular mission or purpose (such as carrying out the healing ministry of the church),<sup>141</sup> and the values and moral perspectives of the individuals

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<sup>140</sup> See BEAUCHAMP & CHILDRESS, *supra* note 52, at 38 (stating that "[o]ccasionally, [a conflicts of conscience] situation arises for physicians when a patient refuses a procedure in a context the physician views as medically unconscionable or requests a procedure the physician finds morally objectionable, such as amniocentesis for sex selection or an untested cancer therapy. If a physician wishes to withdraw, his or her conscientious convictions should be respected, and he or she should be free to withdraw—assuming that the requested actions are not among the general responsibilities of physicians. A patient's right of autonomy should not be purchased at the price of the physician's parallel right. These observations hold for other health professionals as well."); GILBERT MEILAENDER, *BIOETHICS: A PRIMER FOR CHRISTIANS* 76 (2d ed. 2005) (observing that "[p]atients need not submit to doctors' recommendations; doctors need not practice what they consider bad medicine[, which is a moral, not just a technical, category,] simply because patients want it").

<sup>141</sup> For instance, Catholic health care, which is led by both religious and lay leadership, is

a ministry of the Catholic Church continuing Jesus' mission of love and healing in the world today. . . . Catholic health care welcomes and respects people of all beliefs and traditions—attending to their body, mind and spirit. . . . Through the [Catholic Health Association of the United States], the ministry raises its collective voice as a passionate voice for compassionate care, calling for justice in quality health care that works for everyone.

who associate through an organization are reflected in the organization's identity and conscience. As one legal scholar has written, "[t]o exclude institutional health providers from conscience clause protection is merely an indirect way of denying the conscience and morality of the individuals whose will and purposes the entities were created to effectuate."<sup>142</sup> Furthermore, should they be forced to choose between being faithful to their mission, values, and ministry and leaving the health care market place, religious providers may be forced to choose the latter.<sup>143</sup>

Additionally, religious organizations, including religious hospitals, are "fundamental entities independent of the state, something that is not true about most nonreligious organizations created for providing services such as health care."<sup>144</sup> Religious institutions and religious hospitals offer a moral vision regarding human life and health that sometimes contrasts with dominant views in society.<sup>145</sup> In doing so, they serve as a check on the

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CATHOLIC HEALTH ASS'N OF THE U.S., *CATHOLIC HEALTH CARE IN THE UNITED STATES* 1 (2012), available at [http://www.chausa.org/Pages/Newsroom/Fast\\_Facts/](http://www.chausa.org/Pages/Newsroom/Fast_Facts/) (follow "additional information" link).

<sup>142</sup> Lynn D. Wardle, *Protecting the Rights of Conscience of Health Care Providers*, 14 J. LEGAL MED. 177, 186 (1993).

<sup>143</sup> When confronted with the choice between remaining faithful to their mission and values and complying with inflexible government requirements, some faith-based and faith-affiliated institutions have recently determined it necessary to close agencies and discontinue services rather than act in a manner contrary to their mission and values. See, e.g., Laurie Goodstein, *Illinois Bishops Drop Program Over Bias Rule*, N.Y. TIMES, Dec. 29, 2011, at A16 ("Roman Catholic bishops in Illinois have shuttered most of the Catholic Charities affiliates in the state rather than comply with a new requirement that says they must consider same-sex couples as potential foster-care and adoptive parents if they want to receive state money. The charities have served for more than 40 years as a major link in the state's social service network for poor and neglected children."). Thus, in such instances, the government's efforts and pursuit of certain goals can actually contribute to a decrease in access to certain services.

<sup>144</sup> Kent Greenawalt, *Refusals of Conscience: What are They and When Should They Be Accommodated?*, 9 AVE MARIA L. REV. 47, 53 (2010).

<sup>145</sup> H. Tristram Engelhardt, Jr., *The DeChristianization of Christian Health Care Institutions, or, How the Pursuit of Social Justice and Excellence Can Obscure the Pursuit of Holiness*, 7 CHRISTIAN BIOETHICS 151, 157 (2001) ("As Christian health care institutions become secularized, moral commitments never to engage in abortion, artificial insemination by a donor, the medical assistance of sexual functions for persons engaged in sexual activity outside the marriage of a man and a woman, physician-assisted suicide, and euthanasia will appear at tension with the primary secular moral focus of health care institutions on recognizing the dignity of all and on providing health care of excellence."); Margaret Monahan Hogan, *Catholic Health Care Institutions: Dinosaurs Awaiting Extinction or Safe Refuge in a Culture of Death*, 7 CHRISTIAN BIOETHICS 163, 166 (2001) ("[H]ealing of physical illness is not always possible. Furthermore the exclusive focus on healing is too narrow and too exclusive a center. It is to buy into the Promethean myth of modern medicine that offers the promise of human salvation in more and better medicine. Jesus healed but he also suffered and died. Here Catholic health care institutions have special obligations because of the Jesus revealed in Scripture. Catholic health care institutions must be places of caring for the dying that is inevitable. And here they must offer visible witness to the truth of the finitude and promise of human existence."); William E. Stempsey, *Institutional Identity and Roman Catholic Hospitals*, 7 CHRISTIAN BIOETHICS 3, 13-14 (2001) ("As secular society tries to engulf sectarian institutions and homogenize them, Catholic health care institutions are increasingly becoming cognizant of the need to express their ideals and

power of government and majorities to define orthodoxy and mandate any view of the world and life.<sup>146</sup>

In making their judgments regarding certain items and services that they cannot morally provide, individual and institutional providers should nevertheless be mindful of other considerations, including: their duties to patients (including their duty to avoid harm and fiduciary duties as health care providers); patient access to items or services from other providers; and notice and transparency regarding the specific items and services they cannot provide and the reasons supporting their judgment. Providers who conscientiously object should provide notice, disclose their reasons to current and future patients, and provide additional explanation to patients who request more information.<sup>147</sup> Consequently, health care professionals should ensure that their professional judgments are reasonable and explainable to others. They should also provide other care that they do not conscientiously oppose, maintain patient privacy and confidentiality, and provide relevant records to their patients who may seek care from another provider.

### 3. *Freedom of Conscience and the Foundation of Other Rights and Freedoms*

The American people have shown great respect for the rights of conscience throughout this nation's history. *The Williamsburg Charter*, a document drafted and signed by a wide range of civic and religious leaders in celebration of religious freedom on the bicentennial of the call for a religious liberty provision in the United States Constitution, observed:

The right to freedom of conscience is premised not upon science, nor upon social utility, nor upon pride of species. Rather, it is premised upon the inviolable dignity of the human person. It is the foundation of, and is integrally related to, all other rights and freedoms secured by the Constitution. This basic civil liberty is clearly

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distinctiveness. The ideals that these hospitals must express are paradoxical in the eyes of secular society. Catholic hospitals embrace many of the methods of secular medicine as tools in carrying out the healing mission of Jesus Christ while simultaneously recognizing that ultimate healing comes only with the resurrection that follows death.”).

<sup>146</sup> See Carl H. Esbeck, *The Establishment Clause as a Structural Restraint on Governmental Power*, 84 IOWA L. REV. 1, 67–70 (1998) (arguing that religions serve as a check on the power of modern nation-states).

<sup>147</sup> The United States Conference of Catholic Bishops has issued and made readily available a document that outlines the Catholic Church's beliefs and teachings on a range of health care issues. See generally U.S. CONFERENCE OF CATHOLIC BISHOPS, ETHICAL AND RELIGIOUS DIRECTORS FOR CATHOLIC HEALTH CARE SERVICES (5th ed. 2009), available at <http://usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>.



acknowledged in the Declaration of Independence and is ineradicable from the long tradition of rights and liberties from which the Revolution sprang.<sup>148</sup>

In the United States, our fundamental laws expressly protect conscience.<sup>149</sup> For instance, at the federal level, the First Amendment forbids laws that prohibit the free exercise of religion.<sup>150</sup> At the state level, state constitutions protect religious freedom and the rights of conscience.<sup>151</sup> For example, the Indiana Bill of Rights, which follows the pattern of other state bills of rights, recognizes liberty as an inalienable right,<sup>152</sup> and it declares that “[a]ll people shall be secured in the natural right to worship ALMIGHTY GOD, according to the dictates of their own consciences.”<sup>153</sup> The Indiana Constitution also mandates that “[n]o law shall, in any case whatever, control the free exercise and enjoyment of religious opinions, or interfere with the rights of conscience.”<sup>154</sup>

The threats to the rights of conscience and religious liberty are not just politically-established religious and ideological orthodoxies, but also the

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<sup>148</sup> *The Williamsburg Charter: A National Celebration and Reaffirmation of the First Amendment Religious Liberty Clauses*, 8 J.L. & RELIG. 5, 8 (1990). The *Williamsburg Charter* was first drafted in 1988. See APPENDIX B: THE WILLIAMSBURG CHARTER, available at <http://www.freedomforum.org/publications/first/findingcommonground/C02.WilliamsburgCharter.pdf> (last visited Apr. 9, 2012).

<sup>149</sup> See JOHN WITTE, JR., RELIGION AND THE AMERICAN CONSTITUTIONAL EXPERIMENT: ESSENTIAL RIGHTS AND LIBERTIES 39 (2000) (explaining that “liberty of conscience was the general solvent used in the early American experiment in religious liberty. It was almost universally embraced in the young republic—even by the most rigid establishmentarians.”).

<sup>150</sup> U.S. CONST. amend. 1; see also Michael W. McConnell, *The Origins and Historical Understanding of Free Exercise of Religion*, 103 HARV. L. REV. 1409, 1480–1503 (1990) (discussing the framing of the First Amendment to protect the free exercise of religion and the framers’ decision not to extend protection to the rights of conscience).

<sup>151</sup> For instance, Article II of the Declaration of Rights in the Constitution of Pennsylvania of 1776 affirmed:

That all men have a natural and unalienable right to worship Almighty God according to the dictates of their own consciences and understanding: And that no man ought or of right can be compelled to attend any religious worship, or erect or support any place of worship, or maintain any ministry, contrary to, or against, his own free will and consent: . . . And that no authority can or ought to be vested in, or assumed by any power whatever, that shall in any case interfere with, or in any manner controul [sic], the right of conscience in the free exercise of religious worship.

*Constitution of Pennsylvania—Sept. 28, 1776*, AVALON PROJECT available at [http://avalon.law.yale.edu/18th\\_century/pa08.asp](http://avalon.law.yale.edu/18th_century/pa08.asp); see also PA. CONST. art. 1, § 3. Article VIII of Pennsylvania’s 1776 Constitution recognized the right of and protected against government compulsion of those conscientiously opposed to bearing arms. *Constitution of Pennsylvania—Sept. 28 1776*, *supra*; see also PA. CONST. art. 1, § 21.

<sup>152</sup> IND. CONST. art. I, § 1.

<sup>153</sup> *Id.* § 2.

<sup>154</sup> *Id.* § 3.

encroaching mandates of government. Even when government mandates are not raw, thoughtless exercises of power, such mandates, when not carefully calibrated or judiciously tailored to accommodate other concerns, can be just as deleterious. As *The Williamsburg Charter* explained:

Less dramatic but also lethal to freedom and the chief menace to religious liberty today is the expanding power of government control over personal behavior and the institutions of society, when the government acts not so much in deliberate hostility to, but in reckless disregard of, communal belief and personal conscience. . . . [E]ven in America where state-established orthodoxies are unlawful and the state is constitutionally limited, religious liberty can never be taken for granted. It is a rare achievement that requires constant protection.<sup>155</sup>

Furthermore, people of conscience and religious faith have contributed much good in our society. They have led movements to abolish slavery, recognize civil rights, and end poverty. Religious health care institutions have a long history of granting access to health care to the vulnerable, the marginalized, and the underserved in our society. Protection of their conscience in health care settings is warranted to permit them to do what they believe they are called to do in the way they believe they are called to do it.

Given the time-honored respect for conscience in America, the important values at stake for both health care professionals and institutional providers, and the innumerable contributions of people of conscience and faith, we would do well as a society to better reconcile our goals of increasing access to health care, reducing barriers, and securing an environment in which individuals can pursue their own goods with our protection of the rights of conscience. A federal statute that sensibly protects and reasonably accommodates the rights of conscience of health care providers (both individual and institutional) is warranted to observe and help to define and safeguard this boundary area.<sup>156</sup>

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<sup>155</sup> *The Williamsburg Charter*, *supra* note 148, at 9 (paragraph division omitted).

<sup>156</sup> In his commencement address on May 17, 2009, at the University of Notre Dame, President Obama acknowledged the need for conscience protection in federal law, stating: "Let's honor the conscience of those who disagree with abortion, and draft a sensible conscience clause, and make sure that all of our health care policies are grounded not only in sound science, but also in clear ethics, as well as respect for the equality of women." President Barack Obama, Remarks by the President in Commencement Address at the University of Notre Dame (May 17, 2009) (transcript available at <http://www.whitehouse.gov/the-press-office/remarks-president-notre-dame-commencement>). Despite the passage of comprehensive health care reform legislation within a year of the President making these remarks, the need for "sensible" conscience protection in health care remains.

## V. CONCLUSION

Over the last century, our understanding of the physician-patient relationship, the hospital-patient relationship, and the insurer-insured relationship has evolved from a view that these relationships are a matter of private ordering governed by private law to a hybrid blend of private and public ordering governed by private and public law. During this same period, various developments in state and federal law have increased access to health care by reducing barriers and increasing the availability of health insurance and helped to secure an environment in which individuals can pursue their own goods. Initiatives in the ACA contribute to these same policy efforts.

However, even as we continue to make progress in expanding access to health care and securing an environment in which individuals can pursue their own lives and health, we must be careful not to lose sight of other important considerations, values, and principles that need to be preserved in health care. This Article has highlighted some of these other considerations, values, and principles as they relate both to the professional provider's judgment regarding medical necessity, effectiveness, and appropriateness, and to the judgment of individual and institutional providers on matters of conscience in the provision of health care. These two sets of judgments mark boundary areas that legitimately define limits on access to health care.

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Executive Order 13,535, which President Obama signed on March 24, 2010, one day after he signed the Patient Protection and Affordable Care Act, "establish[ed] a comprehensive, Government-wide set of policies and procedures to achieve th[e] goal [of ensuring that federal funds are not used for abortion services (except in cases of rape or incest, or when the life of the woman would be endangered)] and to make certain that all relevant actors—Federal officials, State officials (including insurance regulators) and health care providers—are aware of their responsibilities, new and old." Exec. Order 13,535, 75 Fed. Reg. 15,559 (Mar. 24, 2010). Although this executive order referenced conscience protections in federal laws, including the Church Amendment and the Weldon Amendment, it did not broaden or deepen the protection of conscience for health care providers under federal law.